

Awakening From the Cocoon: Family Members Transitioning Through 100 Days Post
Stem Cell Transplant

by

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Abstract

A qualitative phenomenological study using van Manen's human science method was conducted to gain insight into the lived experience of patients and their family members transitioning through one hundred days post haematopoietic stem cell transplantation (HSCT). Three families between zero and five years post HSCT were recruited from a bone marrow transplant unit in central Canada. Multiple in-depth open-ended interviews and field notes were employed to arrive at a detailed description of the lived experience of patients and family members. Awakening from the cocoon emerged as the main essence of patient's and family members' experiences, supported by three themes: the disruptions, the chrysalis, and new beginnings. The results from this study provide evidence that the families viewed the HSCT in a positive perspective and highlight the importance of supporting families throughout the acute phase of transplantation

keywords: stem cell transplantation, lived experience, qualitative research,
phenomenology

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Dedication

This thesis is dedicated to all the patients and family members who have undergone a stem cell transplant and specifically those who generously shared their stories with me.

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Chapter One: Introduction

Background

Advances in treatment, technology and disease management in oncology resulted in significant improvements in cancer patient survival rates (Jemal, Siegel, Ward, Hao, Xu, & Thun, 2009). In Manitoba, there are 34,000 people living with cancer and this number is projected to increase by 32 % to 45,000 in 2010 (CancerCare Manitoba, 2009). One field having seen considerable progress is the area of haematopoietic stem cell transplantation (HSCT) (Copelan, 2006; Cutler & Antin, 2005; Liesveld, 2000; Niess & Duffy, 2005), referring to a procedure formerly known as a bone marrow transplant (BMT) (Saria & Gosselin-Acomb, 2007).

Improvements in disease therapy, supportive care, graft-versus-host disease treatment, and an understanding of the human leukocyte antigen (HLA) system have resulted in significant advancements in HSCT over the past 50 years. These developments in technology, disease treatment and management have allowed HSCT to become commonplace in contemporary medicine (Cutler & Antin, 2005; Ezzone, 2009; Saria & Gosselin-Acomb, 2007; Schmit-Pokorny, 2009; Shivnan, Shelton, & Onners, 1996) with approximately 50,000 transplant being undertaken annually worldwide (Ferrara et al., 2007). In Manitoba, over 709 adult BMT\ HSCT have been performed since the inception of the Manitoba Blood and Marrow Transplant program in 1990 (CancerCare Manitoba, 2009).

HSCT has been used for numerous years primarily for the treatment of haematological malignancies such as, leukemias, lymphomas and multiple myeloma. However, other less common indications are solid tumours and autoimmune disorders

(Copelan, 2006; Cutler & Antin, 2005). As advancements in research and medicine continue to evolve and indications for HSCT continue to change (Schmit-Pokorny, 2009), gaining an increased understanding of the issues and needs of this unique patient population and their families is crucial. This knowledge may be gained by understanding the perspectives of the HSCT recipients and their families.

Significance of the Problem

Patients undergoing a HSCT usually receive higher than normal doses of chemotherapy with or without total body irradiation (TBI), requiring an admission to a transplant centre during the acute phase of treatment (Rimkus, 2009). The effects of conditioning regimens remain for at least 100 days post HSCT. Typically during the acute phase of a HSCT, the recipient is at risk for significant life threatening complications such as; posterior reversible encephalopathy, thrombotic microangiopathy, graft-versus-host disease, reactivation of human herpes viruses and cytomegalovirus, pulmonary fibrosis, hepatic veno-occlusive disease, infections and renal dysfunction (Copelan, 2009; Cutler & Antin, 2005; Ezzone, 2009; Léger & Nevill, 2004; Rimkus 2009; Saria & Gosselin-Acomb, 2007). Given these life-threatening illnesses and their associated complications resulting from this procedure, this transition period may be characterized by psychological and psychosocial struggles for both the recipients and their families.

A cancer diagnosis and its prescribed treatment psychologically and psychosocially affect the patient and the whole family unit (Helseth & Ulfsaet, 2003; Plant, 2008; Rivera, 1997), creating fear, support needs, and disrupting numerous aspects of their lives (Koegh, O'Riordan, McNamara, Duggan, & McCann, 1998; Yates, 1999).

Family members may find themselves isolated from their customary support systems consequently generating coping and adaptation problems, forcing the acquisition and juggling of numerous roles which were previously the responsibility of the patient (Koegh et al., 1998; Rivera, 1997; Wochna, 1997). The acquisition and redistribution of roles adds to the personal, interpersonal stress and anxiety of family members, further increasing familial stress. This increase in familial stress may disrupt the family's stability and possibly cause relationships to dissolve (Wochna, 1997). The family is crucial during the hospitalization and recovery periods for patients undergoing a HSCT (Plant, 2008; Zabora, Smith, Baker, Wingard, & Curbow, 1992).

The family significantly impacts the HSCT recipient's recovery. Belec (1992) found that the family had the greatest positive influence on the transplant recipient's overall quality of life (QOL). Similarly, Molassiotis, Van Den Akke, and Boughton (1997) found that social supports and family relationships contributed to higher levels of QOL and stress filters. The family's influence on recovery is not limited to QOL. Molassiotis and colleagues (1997) state the HSCT recipient's overall psychosocial adjustment is significantly associated with stronger family relationships. The family significantly impacts the recipient's transplant experience, adjustment, and well being and in turn the recipient impacts the caregiver and family unit (Fife, Monahon, Abonour, Wood, & Stump, 2009).

The recipient and family experience the HSCT in tandem. In Cooke, Gemmill, Kravitis and Grant (2009) the illness trajectory determined how the caregiver responded to caregiving. Higher caregiver distress was associated with greater recipient symptom distress (Fife et al., 2009). Family distress was also reported greatest prior to and directly

after transplant (Koegh et al., 1998) related to increased demands, fears, and disruptions in family routines (Futterman, Wellisch, Zighelboim, Luna-Raines, & Weiner, 1996; Grimm, Zawacki, Mock, Krumm, & Frink, 2000). This imposes significant functional, psychological, and social responsibilities on family members.

While the psychological and psychosocial effects of HSCT on patients have been the focus of a number of studies, the effects on the family unit have received less attention (Koegh et al., 1998; Wochna, 1997). As well, a limited number of studies have been undertaken examining the effects of HSCT on the patient and family as a whole unit. Grundy and Ghazi (2009) identified patient and family experiences as one priority in haemato-oncology nursing. Nonetheless, the Institute of Medicine (2007) identified that in the current health care climate, meeting the psychosocial needs of cancer patients and families is the exception.

To ensure successful caregiving in the home, knowledge and skill enhancement of family systems coping are seen as necessary (Longman, Atwood, Sherman, Benedict, & Tsu-Ching, 1992). Before developing innovative and effective interventions to meet their diverse needs, enhancing our current understanding of patients and families transitioning through the 100 day period post HSCT is required. A qualitative phenomenological approach is appropriate for this study as phenomenology “aims to gain a deeper understanding of the nature or meaning of everyday experiences” (van Manen, 1990, p. 9). This is needed to arrive at a more comprehensive understanding of their lived experience in order to develop appropriate interventions to meet the diverse psychosocial needs of patients and families.

This study provided a detailed description of the transition experience during the first 100 days post HSCT from an insider's perspective of both the recipient and their family members. This account serves to inform health providers caring for both recipients and their family members transitioning through this period by enhancing their understanding of the lived experience.

Purpose and Objectives

The primary purpose of this qualitative phenomenological study was to gain insight into patients and their family members lived experience as they transitioned through one hundred days post HSCT. This study was guided by the following several research questions:

1. How do patients who have undergone HSCT experience transition during the first one hundred days post HSCT?
2. How do families of patients who have undergone HSCT experience transition during the same period?
3. What are the similarities and differences in the meaning of the transition experience between patients who have undergone HSCT and their family?

Assumptions and Preliminary Work

My experience as an oncology nurse on a hematology/acute leukemia and bone marrow transplant unit has provided me with an understanding of what it is like to care for acutely ill patients and their families throughout the BMT\HSCT continuum. The nurses working within this environment provide care to families and patients with a life threatening illness. These patients frequently require a moderate to long hospitalization post HSCT at a transplant centre as a result of their treatment regimen. During the acute

phase of the HSCT setbacks are all too common as a result of life threatening complications and/or infections. Throughout this difficult and arduous experience, the lives of family members frequently become intertwined with their loved one. Considering the interdependent relationship between the patients and family members, it is essential that ongoing support is provided.

My work with BMT\HSCT patients and family members frequently resulted in countless informal discussions about their experiences throughout the continuum, from initial diagnosis to numerous years post HSCT. Patients and families shared personal stories and anecdotes about their experiences pre and post HSCT.

I believe caring for these patients and their families is often a challenge for nurses working on the transplant unit. This challenge arises from several possible reasons. Nurses caring for these patients require advanced knowledge in the area HSCT. This focus on the physiological aspects of the HSCT and its medical management overshadow the psychological and psychosocial needs of these patients. Secondly, nurses focus their care on the patient, thus neglecting the needs and demands of the individual family members. Lastly, patients admitted to the transplant unit may be discharged prior to 100 days post HSCT and return to their home or temporary housing if residing outside the city. Other patients may require a temporary admission to intensive care unit to treat some life threatening complications.

I believe enhancing our current understanding of the lived experience of patients and family members serves to assist nurses in their provision of care. Enhancing nurses and other health care professionals understanding will assist them in providing more

comprehensive and compassionate care. This knowledge is essential for family\patient centered care.

My preliminary work and experience reinforce my view regarding the importance that nurse and other health care providers need to understand what it is like for patients and their families transitioning the 100 day period post HSCT.

Assumptions and Definition of Major Constructs

The assumptions for this research study were grounded within a qualitative naturalistic paradigm to enhance our understanding of this human health experience (Creswell, 2007; LoBiondo-Wood & Haber, 2005; Polit & Beck, 2004; Speziale & Carpenter, 2007; van Manen, 1990). Encompassing these assumptions is the belief that HSCT recipients and families experience transition, one of the central concepts in nursing evolving from the metaparadigms of person, environment, health and nursing (Chick & Meleis, 1986; Kralik, Visentin, & van Loon, 2006; Meleis, 2007; Meleis, Sawyer, Im, Hilfinger-Messias, & Schumacher, 2000; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994).

Assumptions for this research study included:

1. There are multiple subjective realities constructed from the participant's perspective. To fully understand a human phenomenon, multiple realities need to be considered.
2. The researcher interacts with the informants in the research study. This mutual interaction influences both the researcher and informant.
3. HSCT recipient and their family are the experts in describing their experience of transition 100 days post HSCT.

4. The recipient and family both experience health and illness transition.

Definition of Major Constructs

For the purpose of this study, four major constructs were identified. These constructs were: transition, family, meaning, and interpretation.

Transition. Transition is a passage or movement from one state or condition to another. This passage is characterized with an entry, a passage and an exit (Chick & Meleis, 1986; Schumacher & Meleis, 1994). Attributes defining this transition as a process include: disconnectedness, perception, and pattern of response (Chick & Meleis, 1986).

Family. A family is a complex interrelated group composed of multiple constructs, who gain meaning through multiple interactions. These interactions are within the family unit and between the family and environment (Eggenberger & Nelms, 2007). Accordingly, HSCT recipient will define the individuals who constitute the family for this research study (McClement & Woodgate, 1998).

Meaning. The meanings being sought after in this research study are those of HSCT recipients and their family members. The HSCT recipients and their family member's meaning may be either: positive, negative or neutral (Shumacher & Meleis, 1994). These meanings are the subjective appraisal of their transition experience and understanding throughout the 100 day period post HSCT (van Manen, 1990).

Interpretation. Goal of interpretation is to describe, capture, and communicate the meaning in the narrative text of the informants being studied (Cohen, Kahn, & Steeves, 2000; van Manen, 1990). This interpretation should capture the essence of the

experience from the perspective of the participants in its fullest and richest complexity (Cohen et al., 2000).

Chapter Summary

Chapter one provided an overview of the rationale for this research study concerning the lived experience of HSCT recipients and their family members transition during the first 100 days post HSCT. There has been limited research conducted which exploring the transition experiences of patients and family members during the acute phase of treatment. As research and technology advances in the area of HSCT and guidelines evolve, a greater understanding of the care for both patients and families is required in order promote and develop interventions to meet their needs and issues.

Chapter Two: Literature Review

Chapter two provides a review of the literature used to establish a foundation for researching the lived experience of patients and family members transitioning through 100 days post HSCT. A review of the research concerning HSCT included the following: an examination of HSCT, its indications and complications at various points post transplantation. The writer explored the impact of cancer on family and the concept of quality of life (QOL) for both the HSCT recipient and family members. Lastly, a review Meleis' transition theory is presented.

Overview of HSCT

Conceived more than fifty years ago, HSCT was intended to treat injuries resulting from irradiation and subsequently employed in cancer treatment (Copelan, 2006; Negrin & Blume, 2006). Over the past years, HSCT has considerably grown as a treatment modality for a variety of malignant, non-malignant and genetic diseases (see Table 2.1) (Copelan, 2006; Cutler & Antin, 2005; Negrin & Blume, 2006; Neiss & Duffy, 2005).

This procedure is performed when a patient's bone marrow is deficient due to either disease or treatment and consists of administering hematopoietic progenitor stem cells after receiving a preparative regime of high dose myeloablative chemotherapy with or without radiotherapy (Neiss & Duffy, 2005; Wright-Kanuth & Smith, 2001). This preparative regime of chemotherapy and radiotherapy eradicates malignant cells along with the patient's own bone marrow. Hematopoietic progenitor stem cells are then used to reconstitute the bone marrow, thus restoring the patient's hematologic and

immunologic functions (Garret & Yoder, 2007; Negrin & Blume, 2006; Neiss & Duffy, 2005; Shivan et al., 1996).

Table 2.1

Copelan (2006) Common Indications for a Hematological Stem Cell Transplant

Autologous stem cell transplantation	
Multiple myeloma	Ovarian cancer
Non-Hodgkin's lymphoma	Germ-cell tumors
Hodgkin's lymphoma	Autoimmune disorders
Acute myeloid leukemia	Amyloidosis
Neuroblastoma	
Allogeneic transplantation	
Acute myeloid leukemia	Aplastic anemia
Acute lymphoblastic leukemia	Paroxysmal nocturnal hemoglobinuria
Chronic myeloid leukemia	Fanconi's anemia
Myelodysplastic syndromes	Blackfan-Diamond anemia
Myeloproliferative disorders	Thalassemia major
Non-Hodgkin's lymphoma	Sickle cell anemia
Hodgkin's lymphoma	Severe combined immunodeficiency
Chronic lymphocytic leukemia	Wiskott-Adrich syndrome
Multiple myeloma	Inborn errors of metabolism
Juvenile chronic myeloid leukemia	

Sources of Hematopoietic Stem Cells

Hematopoietic stem cells used to re-establish the bone marrow may come from several sources: the bone marrow, peripheral blood (Devine & DeMeyer, 2003; DeMeyer, 2009; Negrin & Blume, 2006; Neiss & Duffy, 2005) or an umbilical cord (Frey, Guess, Allison, & Kurtzberg, 2009; Negrin & Blume, 2006; Neiss & Duffy, 2005). Initially, hematopoietic stem cells were collected from the bone marrow (Neiss & Duffy, 2005) thus, requiring a surgical procedure or intervention. Stem cells were harvested from donors by repeatedly inserted large-bore needles into the iliac crest under general anesthesia (Liesveld, 2000) until 0.5 to 1 L of bone marrow was collected depending on the size of the donor and recipient (Schmit-Pokorny, 2009).

Advances and innovations in collection techniques allowed stem cells to be mobilized out of the bone marrow and into the circulating peripheral blood in sufficient numbers to provide a transplant. This peripheral mobilisation is achieved by administering growth stimulating factors, granulocyte colony-stimulating factor over 4 to 5 days prior to the harvest. If the number of stem cells is sufficient, they are collected from the donor through apheresis (Appelbaum, 2003; Neiss & Duffy, 2005) by extracting the necessary stem cells and returning the remaining blood cells and plasma to the donor (Liesveld, 2000).

Additionally, a more recent method of collection is the harvest of hematopoietic stem cells from the umbilical cord of a baby following delivery. The stem cells are harvested from the placenta and umbilical cord of newborns at birth without any risk to the mother and baby donor (Appelbaum, 2003; Frey et al., 2009; Neiss & Duffy, 2005). The collected stem cells are HLA typed, cryopreserved, and stored in cord blood banks (Appelbaum, 2003; Neiss & Duffy, 2005). These several collection techniques are employed in various types of HSCT.

Types of HSCT

Hematopoietic stem cells may be collected from several possible donors either the patient (autologous HSCT), a family member or unrelated donor (allogeneic HSCT), or an identical twin (syngeneic HSCT) (Appelbaum, 2003; Copelan, 2006; Cutler & Antin, 2005; Devine & DeMeyer, 2003; Garret & Yoder, 2007; Negrin & Blume, 2006; Neiss & Duffy, 2005; Shivnan et al., 1996). Autologous transplantation refers to using stem cells that are collected from the patient himself. Once the stem cells are collected, they are stored by a cryopreservation process until they are required at a later time, typically

during stem cell rescue (Appelbaum, 2003; Léger & Nevill, 2004; Negrin & Blume, 2006; Neiss & Duffy, 2005).

Allogeneic transplantation uses stem cells collected from a related or unrelated donor and is usually the modality of choice for patients who have genetic diseases or a damaged bone marrow (Appelbaum, 2003; Negrin & Blume, 2006; Neiss & Duffy, 2005). Donors and recipients are matched through a process called human leukocyte antigen typing. This matching is a crucial factor in predicting transplant complications and survival rates (DeMeyer, 2009; Devine & DeMeyer, 2003; Wright-Kanuth & Smith, 2001).

Finally, syngeneic transplantation is an allogenic transplant where the collected stem cells originate from an identical twin. Since identical twins are genetically identical, complications and survival rates for these recipients is similar to patients receiving an autologous transplant (Appelbaum, 2003; Neiss & Duffy, 2005; Wright-Kanuth & Smith, 2001). Regardless of the type of transplantation, recipients receive a preparative regime of chemotherapy with or without radiotherapy. These preparative regimes increase the recipient's risk of developing potentially life threatening complications at various stages of transplantation.

Complications Associated with a HSCT

Patients receiving this procedure usually require higher than normal doses of chemotherapy and may be combined with total body radiation (McAdams & Burgunder, 2005; Rimkus, 2009). These treatments are administered with the purpose of eradicating the cancer and consequently damage healthy organs resulting in potentially life threatening complications, if they are not recognized or treated early. These

complications may occur at any stage of the transplant trajectory (Rimkus, 2009). The transplant trajectory may be divided into 4 phases: conditioning, transplant, early transplant, and long term phases. For the purpose of this study, complications will be discussed for the first several phases of transplantation.

Conditioning phase. Recipients may develop complications during the conditioning phase of transplantation as a result of toxicities from the preparative regimens on healthy organs (Rimkus, 2009). Recipients may develop cardiac complications such as cardiomyopathy and restrictive pericarditis as a result of chemotherapy and total body irradiation usually appearing within a few days to one week of the transplant (Rimkus, 2009). Also patients may develop neurological complications such as seizures, hepatic and renal dysfunctions, all a result of chemotherapy (Rimkus, 2009).

Transplant phase. During the transplant phase, patients may develop toxicities depending on the preparative regimen (Rimkus, 2009). Toxicities are frequently attributed to dimethyl sulfoxide (DMSO), a cryoprotectant agent for stem cell preservation (McAdams & Burgunder, 2005) in autologous, allogeneic transplants and for cord blood stem cells. Recipients may experience bradycardia, abdominal cramping and possibly pulmonary complications during the stem cell infusion (Deliliers, Annaloro, & Deliliers, 2000; Rimkus, 2009). DMSO may cause hemolysis resulting in acute renal failure and pigment nephropathy. However, this may be prevented by hyperhydration pre and post stem cell infusion (McAdams & Burgunder, 2005; Rimkus, 2009).

Allogeneic stem cells are usually infused fresh immediately following the harvest. This results in fewer adverse effects compared to the administration of cryopreserved

stem cells (McAdams & Burgunder, 2005) however, the major risk associated with this type of transplantation results from an ABO incompatibility between the donor and recipient (Rimkus, 2009). This adverse effect is similar to a blood product infusion reaction and can include respiratory and cardiovascular complications such as shortness of breath, hypotension, chest tightness, flushing, nausea and vomiting, hives, or anaphylaxis. These adverse reactions may be prevented through astute monitoring and the administration of antipyretics, antihistamines, antiemetics, and sedatives (McAdams & Burgunder, 2005).

Early transplant period. The short term period immediately following transplantation, usually day 0 to 100 post transplant, is the most critical for both autologous and allogenic HSCT recipients (Deliliers et al., 2000; McAdams & Burgunder, 2005; Negrin & Blume, 2006). During this phase, the patient may experience multiple complications resulting from the preparative regimens while having little to no bone marrow function (McAdams & Burgunder, 2005; Rimkus, 2009). The remaining text in this section will discuss common adverse events in the early transplant period such as mucositis, hemorrhage, infections, acute graft-versus-host disease, venoocclusive disease, and pulmonary complications (Negrin & Blume, 2006). However, elaborating on their treatment and prevention is beyond the purpose of this proposal.

Mucositis resulting from chemotherapy, total body irradiation, and infection occurs in 70 to 100 % of stem cell recipients (Rimkus, 2009; Vera-Llonch, Oster, Ford, Lu, & Sonis, 2007a). This adverse event significantly impacts medical resources, has economic consequences (Fanning et al., 2006; Sonis, 2009; Vera-Llonch, et al., 2007a; 2007b), influences the patient's QOL. Mucositis is regarded as the most difficult issue

from the patient's perspective (Negrin & Blume, 2006), and is disheartening for patients and frustrating for caregivers (Sonis, 2009; Vera-Llonch et al., 2007a). Reducing the severity, duration, and incidence of mucositis may improve patient outcomes (Vera-Llonch et al., 2007b).

Prolonged thrombocytopenia places a patient at a significant risk for haemorrhage however; life-threatening bleeding complications are relatively uncommon (Negrin & Blume, 2006). Thrombocytopenia in patients results from the administration of antineoplastic agents in the preparative regimens for allogeneic and autologous HSCT (Johnson & Quiett, 2005). Petechiae, epistaxis, urinary and gastro-intestinal bleeding are common sequelae seen in patients and are easily control with minor interventions (Johnson & Quiett, 2005; Negrin & Blume, 2006).

Infections are the most common sequelae following autologous and especially allogeneic HSCT. HSCT recipients are at an increased risk of infection with bacterial, viral, fungal, and parasitic organisms (Negrin & Blume, 2006; Rimkus, 2009). The administration of chemotherapy with or without radiation impairs the immune system of the HSCT recipient resulting in neutropenia. This period of neutropenia combined with other complications as a result of transplantation (impaired skin and mucosal integrity, graft-versus-host disease, steroid therapy, malnutrition, invasive venous catheters) increase the transplant recipient's mortality and morbidity (Deliliers et al., 2000; Johnson & Quiett, 2005; Negrin & Blume, 2006). Despite advancements in limiting neutropenia, infections are still the leading cause of post-transplant mortality and morbidity (Johnson & Quiett, 2005).

Acute graft-versus-host disease is a serious and challenging complication following allogenic HSCT (Mitchell, 2005; Negrin & Blume, 2006; Rimkus, 2009) usually occurring within the first 100 days post transplant (Negrin & Blume, 2006; Rimkus, 2009). GVHD begins at the time of engraftment when immunologically competent donor-derived T lymphocytes from the graft are recognized as foreign the antigens and cells in the transplant recipient or host and mount an immunologic attack causing varying degree of damage to the recipient tissues primarily affecting the skin, gastrointestinal tract and the liver (Mitchell, 2005; Negrin & Blume, 2006; Rimkus, 2009). Acute GVHD occurs in 20% to 50% of patients receiving an allogenic transplant, with a high risk of mortality in patients diagnosed with severe acute GVHD (Negrin & Blume, 2006) and adversely affecting the overall success of the allogenic HSCT (Mitchell, 2005).

One of the most feared complications in autologous and allogenic HSCT is venoocclusive disease (VOD) (Negrin & Blume, 2006). The incidence of VOD ranges from 0% to 70% (Anderson-Reitz & Mechling, 2005) depending on the criteria used for the diagnosis (Negrin & Blume, 2006) with a high mortality rate of 47% (Anderson-Reitz & Mechling, 2005). VOD results from hepatic venular and sinusoidal endothelial injury, leads to cytokine and tumor necrosis activation, which stimulates coagulation and thrombosis within the hepatic venules and sinusoids. This results in impaired blood flow leading to hepatic VOD (Anderson-Reitz & Mechling, 2005; Rimkus, 2009).

Patients may develop pulmonary complications as a result of damage to the pulmonary capillary bed following chemotherapy and radiation therapy (Negrin & Blume, 2006; Rimkus, 2009) resulting in significant morbidity and mortality following

transplant (Keller, 2005). Pulmonary complications may include idiopathic pneumonia, chemotherapy and radiation therapy associated toxicity, pulmonary embolism, pulmonary edema and infection (Rimkus, 2009; Yen, Lee, Krowka, & Burger, 2004).

This complex procedure is frequently associated with a long recovery period and accompanied with numerous physical and psychological setbacks (Cooke et al., 2009). This strenuous and unique exploit is potentially the basis for prolonged psychological distress for patients and families unlike other oncology patients (Andrykowski, 1994).

Cancer and the Family

Cancer is a stressful and potentially life threatening event significantly impacting the patient's social environment. Family is defined as a social unit with shared beliefs, history and goals (Gilgun, Daly, & Handel, 1992; Whall & Fawcett, 1991) therefore; cancer's impact is not limited to the patient but has ramifications on spouses, caregivers, children and friends. The repercussions of cancer influence the patient and family members along the cancer trajectory, from diagnosis to rehabilitation (Mellon, 2002; Milne, Marcia, & Lynch, 2007; Rivera, 1997; Stetz, McDonald, & Compton, 1996). The diagnosis of cancer is often a crisis resulting in numerous positive and negative reactions. These may include role adjustment problems, altered relationships, psychosocial and psychological problems (Gorman, 2006; Shell & Kirsch, 2001).

Family members experience a multitude of fears and support needs associated with the diagnosis of cancer and its required treatment. The cancer trajectory and its implications are burdensome and traumatic for families, resulting in numerous aspects of their life being disrupted (Feldstein & Rait, 1992; Koegh et al., 1998; Yates, 1999). Family members often find themselves isolated from their customary support systems

during the hospitalization, consequently generating coping and adaptation problems (Gorman, 2006; Shell & Kirsch, 2001; Wochna, 1997).

Role Disruption

This refers to the disruption of roles within the family unit. The family member undergoing treatment for cancer frequently depends on their family for assistance (Barsevick, Much, & Sweeney, 2000). These individuals spend a tremendous amount of time in hospitals, hence causing instability within the family unit. As technology advances within the fields of diagnosis and treatment, medical management becomes more complex (Given, Given, & Kozachik, 2001) frequently requiring the patient to depend on family members for assistance in care, medical treatments and transportation. The patient's increased reliance on family members for assistance forces the acquisition and juggling of numerous roles which they may not have been ready or prepared to acquire (Barsevick et al., 2000; Keogh et al., 1998; Lewis, 1986; Rivera, 1997; Stetz et al., 1996; Wochna, 1997). During hospitalization and once discharged, healthy family members acquire roles and tasks that were the originally the responsibility of the patient (Futtermann et al., 1996; Keogh et al. 1998) along with other roles once the responsibility of healthcare providers. As changes occur within the healthcare system, patient care is increasingly being transferred from inpatient to outpatient settings, requiring families to provide complex medical care (Feldstein & Rait, 1992; Given et al., 2001). Wochna (1997) illustrates this when "a man is admitted for a BMT to cure his leukemia, his wife may have to assume the role of primary breadwinner" (p. 246). The acquisition of new roles adds to the personal, interpersonal stress and anxiety of family members in an already complicated circumstance. The increase stress associated with role redistribution

and acquisition disrupts the family's stability and consequently may cause family relationships to dissolve (Huizinga, van der Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Wochna, 1997). The implications of role redistribution are not limited to the spouses or caregivers. This redistribution of roles may significantly impact the patient's children.

Impact on Children

The impact of cancer is not limited to the patient and spouse. Children of a parent with cancer will experience numerous changes in their lives. These disruptions will impact the children depending on their cognitive, emotional, and social development (Lewandowski, 1996). The cancer diagnosis of a parent disrupts the parent-child relationship often creating psychosocial problems for the children. A children's sense of security will be affected when a parent is diagnosed with cancer. The disruption in this security relationship between the parent and child may potentially create psychiatric disorders later in adulthood (Huizinga et al., 2003; Plant, 2008). Children of a parent who has cancer may develop temporary behavioural problems during the acute phase of the cancer; however other problems may endure much longer (Huizinga et al., 2003) and possibly be reflected in the child's personal and social life. The child may experience difficulties at school, at recreational activities, at home, with parents and friends (Gorman, 2006; Helseth & Ulfaet, 2003; Huizinga et al., 2003).

Often children will need to assume additional responsibilities and tasks within the home. This acquisition of roles and tasks impacts the children's personal time, resulting in less time for playing, homework and recreational activities (Davey, Askew, & Godette, 2003; Huizinga et al., 2003). This burden causes distress in children which is often not

recognized by parents (Helseth & Ulfaet, 2003; Huizinga et al., 2003; Lewandowski, 1996).

Younger children may be more affected because the separation from hospitalisations and changes in family routines (Helseth & Ulfsaet, 2003; Lewandoski, 1996). Children may react negatively to the parent's cancer diagnosis resulting in the development of anti-social and attention seeking behaviour, changes in mood, socialization, and anxiety levels (Helseth & Ulfsaet, 2003). Some researchers suggest that adolescents may be more affected because of their developmental stage and ability to understand the implications related to a parental cancer diagnosis (Davey et al., 2003).

Altered Family Social Supports

Patients receiving a HSCT require a lengthy hospitalization at a transplant centre. The hospitalisation isolates the patient and the caregiver from their formal and informal support systems. Infection control precautions required for these immunocompromised patients and the distance of the transplant centre from the family home are the potential sources of isolation of the family member undergoing the transplant (Wochna, 1997).

During hospitalization family members are isolated from other patient's and their families, in addition to their formal and informal support systems. This degree of isolation brings about increase psychosocial problems: anger, anxiety, confusion, depression, fatigue, mood disturbances and feelings of separation (Boyle, 2006; Grimm et al., 2000; Toseland, Blunchard, & McCallion, 1995; Wochna, 1997).

Disrupted Family Rituals

The diagnosis of cancer and its treatment disrupts family life. Wochna (1997) states that family members of cancer patients will delay life events and change their daily

routines as a result of the increase time spend at the transplant centre, the distance of the transplant centre from the home and the infection control precautions. Maintenance of family rituals and routines are essential in maintaining healthy family functioning (Patterson & Garwick, 2003).

Family Distress

Family distress is reported greatest prior to and directly after transplant (Koegh et al., 1998). Some instances, distress may be more elevated in family members than the patient (Plant, 2006). Some family members experience a higher level of distress related to increase demands placed by other family members, the patient's demands, fears, and disruptions of family routines (Futtermann et al., 1996; Grimm, et al., 2000). The distress experienced by family members may originate in seeing a loved one vulnerable and fearful. McCausland and Cavanaugh (2001) identified sources of distress for family members of lung transplant patients is the waiting for the transplant, the patient's declining health and work. Family members of cancer patients identified fear of recurrence as a major concern and a cause of distress. Fear of recurrence leads family members to question the patient's mortality, survival and prognosis. The fear of recurrence is often more traumatic than the original diagnosis (Gorman, 2006; Sherman & Simonton, 1999).

Communication

This theme examines communication within the family. The diagnosis of cancer significantly impacts the family creating social problems within the family. These social problems may be compounded with communication difficulties surrounding cancer

diagnosis and treatment (Plant, 2008). The difficulties surrounding communication within the family may alter the family's dynamics (Gorman, 2006).

Helseth and Ulfsest (2003) identified that children were reluctant to discuss their feelings with others. This reluctance to discuss feelings is to protect their parents (Davey et al., 2003). Possibly leading parents to underestimate the distress level of experienced by their children when a parent has cancer. In another study by Thastum, Munch-Hansen and Romer (2006), parents identified improved family functioning and decreased emotional distress resulting from a more open communication and sharing of illness-related emotions. Davey and colleagues (2003) identified that adolescents wanted to be informed about treatments, appointments, and condition. The adolescents actively sought information about treatment from various sources (books, pamphlets, internet).

Facilitating Adaptation

The family's adjustment and adaptation is affected by numerous factors. Grey, Knaft, and McCorkle (2006) state that families who have sufficient resources, social supports and hardiness will adjust and adapt better to a chronic illness. Family social supports are vital for the adjustment of family members through the stem cell transplant (Molassiotis et al., 1997). As Wu, Mu, Tsay, and Chiou (2005) state family social support systems are comprised of medical, extended family, other patient's families, socioeconomic and community supports. These social supports lessen the stress experienced by family members allowing them to adjust and adapt through the transplant. Keogh and colleagues (1998) found that social supports from extended family, friends, religious groups and neighbors kept family members going through the transplant process. Effective family adjustment and adaptation is facilitated through supportive

family relationships, moral-religious orientation and a cohesive family network (Molassiotis et al., 1997).

Quality of Life

HSCT has emerged from an investigational to a leading edge therapy for numerous malignant and non malignant diseases (Cutler & Antin, 2005; Ezzone, 2009; Holmes, 2005; Saria & Gosselin-Acomb, 2007; Schmit-Pokorny, 2009; Shivnan et al., 1996). Early research and clinical practice in the field of BMT focused on medical outcomes which had the greatest impact on relapse rates and disease-free status. The focus on medical outcomes took priority over the recipient's psychosocial adaptation, social reintegration, and QOL. However these traditional medical outcomes are shown to be inadequate in evaluating the overall effectiveness of a HSCT (Holmes, 2005). There is a growing consensus among researchers that measuring medical outcomes along with QOL issues provide a more comprehensive picture of a patient's survival following HSCT (Holmes, 2005) and as such should be essential within the transplant setting.

QOL is not a new concept in health literature and research (Holmes, 2005; Plummer & Molzahn, 2009) however, despite the abundance of research being conducted in this field; there is no single definition of QOL. It is acknowledged that QOL is subjective and multidimensional (Ferrans, 2000) and as such there is an interest in researching QOL issues from a multidimensional view (Andrykowski, 1994).

Health-related quality of life (HRQOL) is a global concept of QOL incorporating the physical, emotional, social and role domains of health and as such may be influenced by the person's perceptions of health (Testa & Simonson, 1996). These perceptions of health are influenced by the person's experience, expectations, and perceptions and as

such are an important patient-based outcome in measuring treatment effectiveness (Testa & Simonson, 1996).

Overall QOL

Overall QOL decreases immediately after transplant reaching a nadir by day 30 for allogeneic recipients (Pidala, Anasetti, & Jim, 2009b) and day 10 to 14 for autologous recipients (Pidala, Anasetti, & Jim, 2009a). Over time QOL will return to baseline for allogeneic recipients by day 100 while values for autologous recipients return to baseline between 3 months and 1 year following the transplant (Pidala et al., 2009a; 2009b). Ongoing improvements may be noted over years with transplant recipients reporting their overall QOL post HSCT as being good (Broers, Kaptein, Le Cessie, Fibbe, & Hengeveld, 2000; Chiodi et al., 2000; Hjermland et al., 2004; Neitzert et al., 1998; Pidala et al., 2009a; 2009b; Whedon, Stearns, & Mills, 1995), despite ongoing problems within certain domains of the health-related quality of life (HRQOL) concept.

Physical Domain

Treatment related toxicities and immunosuppression may cause difficulties with a patient's physical functioning (Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009) affecting their QOL. Physical functioning in transplant recipients usually declines immediately following HSCT, reaching a nadir at 30 to 100 days for allogeneic recipients (Bevans et al., 2006; McQuellon et al., 1998; Syrjala et al., 2004) and 10 days to 6 weeks for autologous recipients (Pidala et al., 2009a; Sherman, Simonton, Latif, Plante, & Enaissie, 2009). Following this decrement in physical functioning gradual improvement is noted at 6 months (Schulmeister, Quiett, & Mayer, 2005), 1 year (Bevans et al., 2006), and at 4 years post HSCT (Bush, Donaldson, Haberman, Dacanay, & Sullivan, 2000).

Continued impairments in physical functioning may be noted in long term survivors (Andrykowski et al., 2005; Kopp et al., 2005).

Despite these improvements, HSCT recipients continue to perceive their physical health as poorer than the normal population (Andrykowski et al., 1995; Andrykowski et al., 1997; Bush et al., 2000) frequently reporting ongoing physical symptoms. Recipients identify ongoing problems with fatigue (Andrykowski et al., 1997; Baker, Zabora, Polland, & Wingard, 1999; Lee et al., 2001; McQuellon et al., 1998; Somerfield et al., 1996; Whedon et al., 1995), sleep disturbances (Andrykowski et al., 1995; Andrykowski et al., 1997; Bush et al., 2000), sexual activity (Andrykowski et al., 1995; Baker et al., 1999; Bush et al., 2000; Lee et al., 2001; Whedon et al., 1995), headaches (Andrykowski et al., 1995), stiff joints (Andrykowski et al., 1995), vision problems (Whedon et al., 1995), and with physical activity (Andrykowski et al., 1995; Sutherland et al., 1997). Transplant recipients can expect continued long term impairments in physical functioning (Pidala et al., 2009a; 2009b).

Emotional Domain

Following HSCT, recipients may experience a high degree of psychological or emotional distress early within the transplant continuum (Neitzert et al., 1998; Trask et al., 2002). Emotional functioning may be compromised prior to the transplant and early post transplant with allogeneic recipients appearing to have high levels of distress prior to transplant (Bevans et al., 2006; McQuellon et al., 1998; Pidala, et al., 2009). Autologous recipients appear to fair better in emotional functioning with impairments being observed from baseline to 1 month (Sherman et al., 2009). Small improvements in emotional functioning may be observed by day 100 (Bevans et al., 2006) and continue to improve

and stabilize through years 2 and 4 post HSCT in allogenic recipients (Bevans et al., 2006; Bush et al., 2000; McQuellon et al., 1998). While emotional functioning in autologous recipients may return to baseline by 3 to 6 months post HSCT (Schulmeister et al., 2005). Even with continued improvements in emotional functioning over time, long term studies indicate that recipients continue to demonstrate impairments in emotional functioning relative to non cancer groups (Andrykowski et al., 2005; Kopp et al., 2005; Pidala et al., 2009b). A study by Baker and colleagues (1999) identified ongoing psychological concerns in the areas of fear about the future and relapse, problems with anxiety and depression, loss of sense of control, being more cautious, and feelings of isolation, guilt, and anger. While another study by McQuellon and colleagues (1998) revealed that 20% of patients continued to have distress at 1 year post HSCT.

Social Domain

Overall HSCT recipients adjust quite well after transplant. However, prior to transplant, a certain subcategory of patients may have significant impairments in social functioning. In a prospective study by Hjermstad and colleagues (2004) found that allogeneic HSCT recipients had significant impairments in social and role functioning prior to transplant compared to population norms. However, despite these impairments, significant improvement in social functioning is seen over time. Social functioning may decline after transplant reaching a nadir at 90 to 100 days for allogenic recipients and at 1 month for autologous recipients post HSCT (Schulmeister et al., 2005; Sherman et al., 2009). Autologous recipients appear to fair better with values returning to baseline by 3 to 6 months (Schulmeister et al., 2005) compared to 1 year for allogenic recipients (McQuellon et al., 1998). Social functioning will progressively improve overtime but

continued impairments will be observed when compared to non-cancer groups (Bevans et al., 2006; Kopp et al., 2005; McQuellon et al., 1998; Sutherland et al., 1997).

Role Domain

Role functioning appears to be lower than population norms prior to HSCT for both autologous (Sherman et al., 2009) and allogenic recipients (Hjermstad et al., 2004). Autologous recipients show a decline reaching a nadir at 10 days (Sherman et al., 2009) while allogenic recipients achieve a nadir at 100 days post HSCT (Bevans et al., 2006; McQuellon et al., 1998). Gradual improvement is noted, with values returning to baseline between 90 days to 1 year post HSCT for autologous recipients (Bevans et al., 2006). Allogenic recipients had continued improvement with values returning to baseline by 1 year (McQuellon et al., 1998). In a study by Lee and colleagues (2001) showed that by 1 year the majority of survivors had returned to work, school or homemaking (61% autologous and 58 % allogeneic recipients) with further improvements noted at 2 years (70 % of autologous and 67 % of allogeneic recipients). Despite these continued improvements, autologous and allogeneic have continued long term impairment in role functioning (Andrykowski et al., 1995; Lee et al., 2001; Pidala et al., 2009a). Andrykowski and colleagues (1995) studied 172 bone marrow transplant survivors (45% allogenic and 55% autologous) post transplant with 52% reporting not having returned to normal post BMT with recipients frequently identifying problems in the area of working.

Family/Caregiver QOL

While numerous research studies explore the QOL of HSCT recipients at various times throughout the transplant trajectory, little attention is paid to their partners and caregivers (Holmes, 2005; Pidala et al., 2009a). Evidence suggests partners and spouses

experience similar disruptions in the physical, psychological and social domains of QOL at levels equal to or greater than recipients at various stages of transplantation. In a study by Bishop and colleagues (2007), partners and survivors reported sleep and sexual problems post HSCT, with partners reporting worse levels of fatigue than survivors. Similarly, Gaston-Johansson, Lachica, Fall-Dickson, and Kennedy, (2004) found that primary caregivers of patients undergoing HSCT experienced low grade fatigue throughout the transplant process.

Caregivers and partners experience psychosocial difficulties pre and post HSCT with caregivers reporting psychological distress at levels similar to patients (Keogh et al., 1998; Siston et al., 2001). A study by Keogh and colleagues (1998) found that 88% of relatives reported considerable psychological distress pre transplant and at 3 months post transplant which was significantly correlated with the patient's physical and psychological wellbeing.

Transition

Transition is a central concept in nursing (Chick & Meleis, 1986; Kralik, et al., 2006; Meleis, et al., 2000; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994) and is defined as a "passage or movement from one state, condition, or place to another" (Chick & Meleis, 1986, p. 239). Often transition is a result of change and this creates instability in the lives of individuals and their families (Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Shumacher & Meleis, 1994), consequently having significant implications on their well-being and health (Chick & Meleis, 1986; Kralik et al., 2006; Meleis, et al., 2000; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994). Clients and their families are vulnerable to risks that may negatively impact their health such as:

problematic or extended recovery, and delayed or unhealthy coping (Meleis et al., 2000; Meleis & Trangenstein, 1994). Nursing is often the primary caregiver of clients and their families during phases of transitions (Shumacher & Meleis, 1994) or are preparing clients and families for impending transitions (Meleis et al., 2000).

People often experience transitions throughout their lives. Four different types of transitions are identified: developmental, health and illness, situational, and organizational (Chick & Meleis, 1986; Schumacher & Meleis, 1994). These different types of transitions are not discrete or mutually exclusive (Meleis et al., 2000), often people may be experiencing at least two or more transitions simultaneously.

Developmental transitions include: parenthood, adolescence, menopause, and childbearing (Meleis & Tragenstein, 1994; Shumacher & Meleis, 1994). Health-illness transitions explore the response of patients and families to illness (Kralik et al., 2005). Situational transitions occur in various educational and professional settings. These may occur in educational programs (Young, 2000), clinical practice, and in families (Meleis & Tragenstein, 1994; Schumacher & Meleis, 1994). Organizational transitions may occur at the individual or family level resulting from changes in society, environment or community (Kralik et al., 2005; Schumacher & Meleis, 1994).

These transitions are often precipitated by significant events that require a client to adapt new patterns of response. The process towards a healthy transition may be facilitated or hindered by the client's environment. The client's environment includes: personal, community and societal conditions (Meleis et al., 2000). Personal meaning, cultural beliefs, socioeconomic status, knowledge, and education impact the transition process. The outcomes of the transitional experience are influenced by the environmental

factors interacting with the individual's perceptions, resources, and state of well-being.

Nursing facilitates the process of healthy transitions. Healthy transitions are identified by outcome indicators: mastery of new skills needed to manage a transition and the development of a fluid yet integrative identity (Meleis et al., 2000).

Limitations of the Literature

The abundance of literature focused on patient's response to cancer. When the impact of cancer on family is investigated, usually this is through individual family members and not the family unit. The literature failed to examine the transition experiences of patients and families during this period. Examining the family unit as a whole may provide greater insight in their experience during the 100 days post HSCT period.

Chapter Summary

The literature highlighted what is known about HSCT to date. HSCT has evolved over the years and has become commonplace in contemporary medicine. As advancements within this field progress, indications for HSCT will continue to change resulting in significant increases in patient survival rates. However, given the treatment related toxicities, HSCT recipients are at significant risks of developing life threatening complications. These life threatening complications significantly impact both the recipient and family members' QOL, given both experience the HSCT in tandem.

To date a significant number of studies have examined the QOL of HSCT recipients at various points throughout the HSCT continuum. However, there are an insufficient number of studies examining the family/caregiver experience within the HSCT process given the family/caregiver may experience poorer QOL compared to the

recipient. This literature review provided support for an in-depth exploration of the lived experience of both recipients and their family members as they transition through the first 100 days post HSCT with an emphasis on their meaning of the experience. The following chapter will review the methodology used to complete this research study.

Chapter Three: Research Methodology

Chapter three discusses the philosophical framework and methodology used for this research study. The research methodology includes the following: the design, sample selection and recruitment, data collection methods, plan for data analysis, measures to ensure rigor and trustworthiness. Finally, ethical considerations, study risks and benefits, and study limitations are discussed.

Research Design

This research study strived approach for this study was appropriate, given little is known (Creswell 1998; 2007) to understand the meaning patients and family members impute to their transition experience 100 days post HSCT using a qualitative approach, given little is known (Creswell 1998; 2007). This research study was concerned with the human experience of a phenomenon. Accordingly, a phenomenological approach was appropriate in answering this research enquiry. Phenomenology is a useful methodology to understand the lived experience of those going through the phenomenon (Cohen et al., 2000; Creswell, 1998; 2007; Speziale & Carpenter, 2007).

Phenomenology is an alternative to the empiricist paradigm (Jones & Chapman, 2000; Munhall, 2007a; 2007b) and seeks to discover and describe the meaning and perceptions of people's life experiences (Annells, 2006; Creswell, 2007; Polit & Beck, 2004). The phenomenological researcher seeks to find out what is the essence of a phenomenon and its meaning (Polit & Beck, 2004; Speziale & Carpenter, 2007; van Manen, 1990). Phenomenology is an appropriate method of inquiry when exploring human experiences, particularly when the purpose of the research is focused on identifying meanings to phenomenon as attributed by the individuals experiencing the

phenomenon. Nursing practice focuses on people's life experience and as such, phenomenology is an appropriate method of inquiry for nursing research (Annells, 1996; Lopez & Willis, 2004; Morse, 1994; Speziale & Carpenter, 2007). Specifically, hermeneutic phenomenology as interpreted by van Manen (1990) will be the research approach used. Van Manen's hermeneutic phenomenology integrates the works of Husserl and Heidegger. In order to develop a true understanding of van Manen's approach, the works of the founding authors will be discussed.

Husserl's Phenomenological Research

First developed by Edmund Husserl (1962), empirical phenomenology focuses on the participant's description of the experience and less on the researcher's interpretation (Annells, 1996; Creswell, 2007; Lopez & Willis, 2004; Polit & Beck, 2004). Husserl's philosophy for phenomenology relates primarily around the question: "How do we know?" (Morse, 1994, p. 118). The investigator sets aside his experiences, attempting an innovative approach to the phenomenon. The methodology consists of identifying the phenomenon of interest, setting aside the researcher's previous experiences, and data collection from a number of individuals who experienced the phenomenon. The information collected is analyzed and reduced to statements and then grouped into themes. The researcher then develops two descriptions of the phenomenon; a textural and structural description. The textural description reflects what the participants experienced, while a structural description recounts the context of the experience. The researcher uses both, a textural and structural description to impart the essence of the phenomenon (Creswell, 2007). An alternative to Husserl's phenomenological approach

was developed from one of Husserl's students. Heidegger's philosophy moved from a descriptive to an interpretive approach.

Hermeneutic Phenomenological Research

The second approach is hermeneutic or Heidegger's phenomenology. Heidegger's inquiry of the lived experience focused on the question "What is Being?" (Polit & Beck, 2004, p. 253). This approach is interested in the human world as it is found (van Manen, 1990), and "how people interpret their lives and make meaning of what they experience" (Cohen et al., 2000, p. 5). Hermeneutic phenomenology is an interpretative process seeking to understand the meaning of phenomena as people experience it. This approach is interested in understanding the life world from the inside, understanding the meaning of everyday experiences, comprehending the essence, and the lived experience of individuals as they live through a phenomenon. Capturing the essence of a phenomenon is central to gaining an understanding of the underlying meaning of the experience (Dowling, 2007; Cohen et al., 2000; Morse, 1994; Speziale & Carpenter, 2007). Heidegger's phenomenological approach places less emphasis on bracketing the researcher's preconceptions compared to Husserl's method during the research process (Dowling, 2007; Lopez & Willis, 2004; Speziale & Carpenter, 2007). The analysis for this research study will be guided by van Manen's (1990) approach. This approach identifies six methodological themes used to design this study (see Table 3.1).

Aim of Hermeneutic Phenomenological Research

Phenomenology does not attempt to predict, do scientific generalization and generate theory (van Manen, 1990). Instead, the aim of phenomenology is to increase the

understanding of phenomena and its' attributed meaning (van Manen, 1990). This methodology is useful to nursing research because it may serve to inform nursing practice (Annells, 1996) and provide meaning to the experience of treatments and nursing care (Jones & Chapman, 2000).

Table 3.1

Van Manen's (1990) Research Process

Van Manen's (1990) Methodological Themes	Research Activities for this Study
Turning to a phenomenon which seriously interests and commits us to the world	Literature review, proposal, recruitment of participants
Investigating experiences as we live it rather than as we conceptualize it	In-depth interviews
Reflecting on the essential themes which characterize the phenomenon	Analysis
Describing the phenomenon through the art of writing and rewriting	Interpretation of emerging themes, writing and rewriting themes
Maintaining a strong and oriented pedagogical (nursing) relation to the phenomenon	Refer to the research question and purpose, nursing experience and literature
Balancing the research context by considering parts and the whole	Movement from themes to the entire transcripts of individual interviews

Appropriateness of Hermeneutic Phenomenological Research

Hermeneutic phenomenology was an appropriate method of inquiry for this study as the inquirer has previous experience and knowledge of the phenomenon of interest. The intent of this research study was to gain an understanding of the lived experience of patient's and their family member's as they transition through 100 days post HSCT. This deeper understanding from an insider's view will assist nurses and healthcare

professionals to understand the lived experience of their clients and family members thus informing nursing practice (Annells, 1996) and enhancing their provision of care (Lopez & Willis, 2004; Munhall, 1994).

Sample Selection, Recruitment, and Setting

Sample Selection

A purposive sampling technique was employed to recruit patients and/or immediate family members from the outpatient adult bone marrow transplant unit at CancerCare Manitoba in Winnipeg, Manitoba. This sampling technique is recommended to develop a rich and dense description of the phenomenon (Speziale & Carpenter, 2007). Originally, participants actively undergoing a HSCT were being recruited for this research study. However, difficulty recruiting participants required this inclusion criterion to be amended and resulted in a modification of the inclusion criterion three for both patient and family members.

Patients met the criteria for this study if they:

- (1) were able to read, write and speak English;
- (2) were 18 years of age or older;
- (3) were between day 0 to 5 years post HSCT.

Family members met the criteria for this study if they:

- (1) were able to read, write and speak English;
- (2) were 18 years of age or older;
- (3) were between day 0 to 5 years post HSCT;
- (4) were defined according to the recipient of the HSCT.

Participant Access

Research ethics approval was received on February 4, 2011 from the University of Manitoba Education and Nursing Research Ethics Board (ENREB) (see Appendix A). Approval from the Research Resource Impact Committee (RRIC) at CancerCare Manitoba (see Appendix B) and the Health Sciences Centre (HSC) Research Impact Committee (see Appendix C) was received in February 2011.

As of May 2012 no participants were recruited for the research study. Amendments were undertaken to the research protocol in order to increase recruitment. These amendments to the protocol's sample recruitment were to extend the inclusion criterion and recruitment method. Approvals for the amendments to the research protocol were received on May 16, 2011 from the University of Manitoba ENREB (see Appendix D) and from the RRIC at CancerCare Manitoba on June 13, 2011 (see Appendix E).

Recruitment

Initially the bone marrow transplant (BMT) nurse clinician assisted in the recruitment of potential informants from the Blood and Marrow Transplant Unit at CancerCare Manitoba. In June 2011 the two post BMT registered nurses were recruited to assist the nurse clinician with recruitment as a result of the amendments to the research protocol. The nurse clinician and registered nurses were provided with an introductory letter describing the purpose and inclusion criteria for the research study (see Appendix F). The researcher met with the nurse clinician and registered nurses to review the research protocol and inclusion criteria (see Appendix G). Once the nurse clinician and registered nurses understood the purpose and inclusion criteria, informed consent was obtained (see Appendix H). The nurses were then provided with a script (see Appendix

I) briefly describing the research study so that it could be read to potential participant prior to giving them an introductory letter (see Appendix J). The patient undergoing the HSCT was the initial contact person and determined family member's participation. If eligible participants were interested in participating in the research study and consented to be contacted, the nurse clinician or post HSCT registered nurses provided the researcher with the names and phone numbers of interested participants. Along with notifying the researcher, the nurse clinician and registered nurses informed potential participants that the researcher would initially contact them by phone.

Snowballing was employed to assist in recruiting potential participants. Participants recruited other participants and served as the initial contact person. The participants provided the researcher's contact information or communicated the potential participant's contact information to researcher. The potential participant was informed that the researcher would contact them by phone.

All the participants contacted the researcher directly by telephone or email. The researcher provided a description of the study to all potential participants using a script (see Appendix K). Participants who met the inclusion criteria and were willing to participate in the research study met with the researcher at a mutually convenient location, date and time.

Sample Size

Over a period of eight months, 5 participants were selected to participate in the research study. Four participants were family members and one participant was a stem cell recipient. In qualitative research, there is no formula to determine appropriate

sample size. Sample size was determined by the researcher, the thesis supervisor and data saturation.

Research Setting

The interviews were conducted where patients and family members desired (e.g., home, in hospital patient room). Four interviews took place at the participant's home and one at the family member's place of work. All the interviews consisted only of the participant and researcher in areas with minimal distractions.

Data Collection Methods

Multiple data collection methods were employed to arrive at a detailed description and understanding of the lived experience of patients and their family members transitioning through 100 days post HSCT. After obtaining informed consent, the various forms of data collection included demographic information, open-ended person centered interviews, and field notes. The series of interviews with patients and family members and the numerous data collection methods assisted in arriving at a detailed understanding of the lived experience of patients and family members.

Informed Consent

Prior to commencing the first interview, the researcher engaged the participants in a formal consent process. Prior to signing the informed consent form, the researcher reviewed the form with the participants (see Appendix L and M). The opportunity to withdraw or end the interview, and refuse to answer any questions was reinforced with the participants during this process. The researcher advised participants that they may renegotiate consent at anytime during the subsequent interviews. This

allowed the participants the option to withdraw from the study should their commitment change (Morse, 1994; Speziale & Carpenter, 2007).

The participants were told that confidentiality would be maintained and that their names and identities would only be known to the researcher. They were instructed that only the researcher and Dr. Roberta Woodgate would have access to the interviews and that Dr. Matthew Seftel and Dr. Susan McClement would only have access to the summary of the aggregate/collective data. Participants were instructed that their identities and interviews would not be shared with physicians, nurses, and other healthcare professionals.

Demographic Data

At the first interview, demographic information (see Appendix N and O) was obtained from all participants prior to the commencement of the interview and audio recording. The participants took between 5 to 10 minutes to complete the demographic form. The data collected from the participants included: their age, gender, marital status, number of children, place of residency, relationship to HSCT recipient, and type of employment. Considering the small sample size, identifying other participant characteristics and attributes would have compromised their confidentiality. The demographic data collected from the forms provided a description of the individual participants and the population of this study.

In-depth, Semi-Structured Interviews

Five participants chose to be interviewed for the research study. Participants were asked to participate in three interviews. One patient and three family members participated in all three interviews while one family member participated in one

interview, declining to participate in the subsequent interviews. These interviews took place between July 2011 and January 2012. Speziale and Carpenter (2007) state that one interview is insufficient to gather rich data. The initial interviews lasted between 50–96 minutes, the second interviews lasted 50-92 minutes, and the third interviews lasted between 30-45 minutes. Consent was continually renegotiated at each subsequent interview. If the participants refused to participate in the study, they were not pursued.

The interviews consisted of semi-structured, open-ended questions that allowed the participants to elaborate on their lived experience (see Appendix P and Q). Using an open-ended interview method allowed participants to fully describe their experience (Speziale & Carpenter, 2007). Prompt questions were formulated if participants needed facilitation in telling their lived experience. The subsequent interviews allowed the participants to elaborate on their previous interview and permitted the researcher to check his understanding and interpretation of what was said during previous interviews. All interviews were conducted and audio taped by the researcher. Audio taping facilitated the analysis of the interviews. The audio taped interviews were transcribed verbatim by a transcriptionist. Qualitative data analysis occurred simultaneously with data collection.

Anecdotal Field Notes

After each interview, the researcher wrote notes documenting the interviews that were part of the data analysis process (Speziale & Carpenter, 2007). The notes included nonverbal behaviors of the participants, assumptions about what was heard, and the researcher's experience during the interview along with interview context, and any procedural problems. The field notes were transcribed by the researcher.

Data Analysis

The goal of phenomenology is to describe a phenomenon as a lived experience. Employing a phenomenological methodology required that data analysis occurred simultaneously with data collection (Speziale & Carpenter, 2007). After transcription, all interviews and anecdotal/field notes were listened to and reviewed several times to immerse the researcher in the data and review for accuracy. The verbatim transcriptions of the interviews were continually reread to identify phrases or statements that seemed to reveal or capture the essence of the phenomenon (van Manen, 1990). Thematic statements were isolated using van Manen's (1990) selective highlighting approach. In this approach the researcher circled, underlined or highlighted statements, phrases or sentences that stood out or seemed to be thematic about the experience. As themes and statements were gathered, these were written in more phenomenologically sensitive paragraphs. The researcher wrote and rewrote the themes thus assisting in the interpretation of the data. Themes were supported by examples from the transcriptions, and anecdotal field notes. Providing supporting examples illustrated how the themes emerged. The resulting themes provided an insight into the phenomenon of interest specifically for these research participants. The essence and themes were described and validated by research participants at the third interview. The demographic data was summarized and described using such descriptive statistics such as percentages and averages.

As this study was part of a Master of Nursing thesis project, collaborative analysis occurred whereby the student's thesis advisor participated in discussions about the essence and themes. They were clarified, examined, and re-interpreted (van Manen,

1990). This provided the researcher with guidance and experience in thematic analysis, but this method ensured that the interpretation of the material was an appropriate representation of what the participants shared. Only the student researcher and the thesis advisor read the interviews and had access to the data.

Measures of Rigor and Trustworthiness

Trustworthiness in qualitative research is measured by how accurately the data represents the participants' experience (Speziale & Carpenter, 2007). The researcher used criteria developed by Lincoln and Guba (1985) to support trustworthiness in this qualitative research study: credibility, dependability, confirmability and transferability.

Credibility

The credibility of a research study refers to how truthful are findings (Lincoln & Guba, 1985). The researcher spent a substantial amount of time with the participants and their families. Four participants were interviewed three times, allowing the researcher to arrive at a detailed representation of their experience. However, one participant was interviewed only once for the research study. These repeated interviews allowed the researcher to confirm interpretations of their experiences from the previous interviews. These activities increased the probability that credible findings may be reproduced.

Dependability

This is partially achieved through meeting credibility (Speziale & Carpenter, 2007). Findings were studied, discussed and reviewed with the thesis supervisor and furthermore helped determine dependability within this research study.

Confirmability

The researcher documented and recorded all activities throughout the research study, allowing the possibility for another researcher to follow (Lincoln & Guba, 1985). The documentation permitted an audit trail and included audio-tapes, anecdotal/field notes, interview transcripts, data analysis, and journaling. This documentation illustrated how the researcher formulated his conclusions.

Transferability

The probability findings from the research study have meaning to others in similar situations. The potential users of the findings may determine the transferability of the conclusions (Lincoln & Guba, 1985). The researcher through documentation and the use of quotes supported the essence and themes that emerged from the research study. This may enlighten the user of the findings to the process used in interpreting the findings.

Ethical Considerations

It is generally recognized that conducting qualitative research is inherently unpredictable given the interaction with human participants. As a result of this unpredictability, ethical dilemmas arise throughout the research process (Speziale & Carpenter, 2007) and must be considered throughout this research study. In order to safeguard the rights of the research participants and to remain ethically sound, the researcher needed to adhere to the following ethical principles; autonomy, non-maleficence, beneficence, justice, and confidentiality. The following described the ethical issues that were considered for this research study.

Ethics Review

The purpose of the ethics committee is to ensure that the research study adheres to ethical principles. In order to maintain the protection of all participants, the researcher obtained human ethics approval from the University of Manitoba Education and Nursing Research Ethics Board (ENREB, Research Resource Impact Committee (RRIC) at CancerCare Manitoba, and the Health Sciences Centre (HSC) Research Impact Committee. In addition to being the researcher in this study, I am also a registered nurse who abided by the Canadian Nurses Association Code of Ethics for Registered Nurses. I have signed a Privacy Health Information Agreement (PHIA) with the Winnipeg Regional Health Authority.

Autonomy. In maintaining the ethical principle of autonomy, it was important to recognize the right of all the participants to freely choose whether to commence and continue with their participation in this research study and, once participation began, to ensure that it remained voluntary. Informed consent was obtained from all participants prior to the start of data collection at the first interview through the signing of a consent form and was continually renegotiated throughout each subsequent interview. The process of informed consent meant that the research participants were thoroughly informed about the research study, comprehended the information provided to them, and were capable to choose whether or not they wished to participate in the study or decline (Speziale & Carpenter, 2007). All research participants were made aware that their participation was voluntary, and they could withdraw at anytime without penalty or effect on their family member's care. Strategies to ensure autonomy in this research study included:

1. No dual relationships were present within the study.
2. Potential research participants were initially notified of the research study by a letter or by an individual having no affiliation with the study. To prevent potential participants from feeling coerced, the researcher did not have access to any names of the stem recipients and their family members until permission to release their names was obtained or the participants contacted the researcher by email or telephone.
3. Research participants were 18 years or older and voluntarily consented to be interviewed.
4. Interviews occurred at a time and location convenient to the research participants. The approximate length of time for the interviews was discussed with each participant prior to obtaining their informed consent.
5. Prior to obtaining their informed consent, a written description of the study's purpose, methods of data collection, and time commitments was discussed with each research participant. My student status, thesis supervisor's name and credentials and university affiliation were described. Contact numbers for both the researcher and the supervisor and the Human Ethics Secretariat were provided. All information about the study was discussed verbally with ample time to answer any questions from research participants. The risks and benefits of this research study were discussed with each research participant prior to obtaining their informed consent.

Non-maleficence. Ensuring the principle of non-maleficence required the researcher to implement strategies that neither the researcher nor the research did any

harm (Polit & Beck, 2004). Given the nature of a phenomenological study and the main purpose of this research study, participants may have been vulnerable to unpleasant feelings, memories and to losing personal and family privacy. As such, it was essential that the researcher maintained an ongoing vigilance towards these issues.

Using in-depth interviews presented both risks and benefits to the research participants. The participants were presented with a discussion regarding the nature of the interview with sufficient opportunities for questions. All the research participants were given the opportunity to withdraw at anytime from the research study.

The potential for distress when recalling past memories was possible within this qualitative studies. This potential for an adverse event required the implementation of an intervention plan prior to commencing the interviews. In the event of unpleasant memories during the interview, the plan was to stop the audiotape, validate the research participant's feelings and provide time. If the participant was able to continue, the audiotape was restarted and the interview commenced again. In the event that the participant was unable to continue, the interview was stopped. The participant was provided with the researcher's phone number and appropriate counseling and debriefing sessions were offered.

Beneficence. The ethical principle of beneficence entails more than doing no harm but doing good (Speziale & Beck, 2007). In research beneficence is enacted through efforts of ensuring maximum benefit for the research participant. Research participants were provided with sufficient information and knowledge to make informed and autonomous choices. All research participants were provided with both written and verbal information concerning the research study and its potential risks and benefits. The

researcher encouraged the participants to ask questions and seek clarifications on an ongoing basis.

Justice. Justice denotes the right of every participant to be treated with what is morally right and proper (Polit & Beck, 2004). In research involving humans, justice refers to distributive justice, which required the researcher to not discriminate or neglect potential individuals or groups who may of benefited from advances in research (Polit & Beck, 2004). The voice of family members of stem cell recipients was lacking in literature. For this study, I hoped that all family members would have the opportunity to participate. The researcher ensured that every attempt was made to include all families willing to participate.

Confidentiality. Issues of privacy, confidentiality and anonymity were discussed during the informed consent process. The in-depth interviews prohibited participant anonymity, however efforts were made to ensure their confidentiality. Eligible and consenting participants were identified by code numbers to maintain their confidentiality and anonymity. All materials containing personal information and research data was kept in a locked filing cabinet and a password protected computer only known to the researcher. Only my thesis advisor and I had access to the field notes, recordings, and transcripts of the interviews. The only other individuals with access to the aggregated summarized transcribed interviews were the thesis committee members. After seven years all data will be completely destroyed. Participant confidentiality and anonymity was maintained during data synthesis and writing by assigning pseudonyms to participants and altering potential information that may have identified a participant.

Risk and Benefits

In addition to the risks discussed earlier, there were potential benefits to sharing their own story and have a lasting effect. According to van Manen (1990) these in-depth interviews may lead “to new levels of self-awareness, possible changes in life-style, and shifting priorities of living” (p. 162). It might be painful for some family individuals to have a family member undergo a HSCT. Participating in the research study and talking about their experience might have made them feel good thus having a beneficial effect (Woodgate, 2006).

There was no financial compensation for participants in this research study. The information and knowledge generated from this study may enhance the lives of stem cell recipients and their family members.

Chapter Summary

This hermeneutic phenomenological research study was designed to gain an understanding of what it is like to transition through 100 days post HSCT. Data was gathered through multiple data collection techniques: in-depth, semi-structured interviews, demographic data, and field notes in order to arrive at a detailed understanding of the transition experience. Data analysis followed van Manen’s (1990) hermeneutic phenomenological approach concurrently with data collection. The following chapter will discuss the results from the research study.

Chapter Four: Results

This chapter will present a description of the patients and family members who participated in this research study. The research study was unable to explore the similarities and differences between patients and family members experiencing this phenomenon due to the participation of only one recipient. The findings from this phenomenological study reflect the lived experience of patients and family members transitioning through one hundred days post stem cell transplant. Thematic analysis revealed the essence is an “*awakening from the cocoon*” for patients and family members as they transitioned through this phase of transplantation. Three themes emerged from the interviews substantiating the essence: “The disruptions”, “The chrysalis”, and “New beginnings”.

Sample Description

The sample consisted of 5 participants (1 patient and 4 family members) recruited from a tertiary hospital in western Canada. The participants were between day 0 and 5 years post HSCT, representing 3 families. One family had an allogeneic HSCT, one had an autologous HSCT and the last family had two transplants, first an autologous followed by an allogeneic HSCT. Of the four family members, one was a husband, two were mothers, and one was a wife. Their ages ranged from 42 to 70 years with a mean age of 55 years. All the family members were married. Two family members resided outside the city of Winnipeg but moved within the city limits for the cancer treatments and HSCT.

The patient was a single, 26 years old, female, and resided within the city of Winnipeg. Considering the small sample size of 5 participants, identifying other participant characteristics and attributes would compromise their confidentiality.

Thematic Analysis

Patients and family members in this study provided a description of their transition experience through one hundred days post HSCT. This transition commenced when the patient received the cancer diagnosis and continued through and post transplantation. The HSCT became a momentous event in their lives, undoubtedly reshaping the participants. Through the patients and family member's description of their HSCT experience, themes emerged depicting their experience and evincing the essence of their lived experience for the first one hundred days post HSCT. Although only one research participant was a stem cell recipient, patient's experiences were gathered from family member participants. The following section will discuss the essence of the phenomenon and the themes communicating the essence will be presented.

The Essence: Awakening from the cocoon

For the participants in this study, the essence of their lived experience as they transitioned through one hundred days post HSCT was an "*awakening from the cocoon*". This was a pivotal period for the patients and their family members. This phase of the transplant trajectory was experienced as a metamorphosis. The metamorphosis involved patients and families going through a journey, from living with the disruptions to living in a cocoon to finally experiencing new beginnings. It is during this period of metamorphosis that the focus was on rebuilding the physical, psychological and psychosocial characteristics of patients and families.

Although this study examined their lived experience from the day of transplantation, day “zero”, up to one hundred days post HSCT, these rich and fascinating experiences continued well beyond this period. Every participant began their interview by conveying their experiences from the moment of diagnosis up to one hundred days post HSCT.

Patient and family members recall the cancer diagnosis as a major life changing event and the beginning of a journey that culminated in transplantation. The length of this odyssey varied between patients. This tumultuous period was associated with numerous “ups and downs” as a result of prognosis, treatments and treatment related complications. This husband conveyed his view of their experience:

... she went and seen her family doctor in [name's town] and they did a blood test and, and um found that her blood was abnormal, in fact they phoned two hours later and told her to get the hospital as soon as possible, to emergency there in [name's town] and that's kind of where our rollercoaster started, our ride from there ... (P003, lines 93 to 100)

This journey forevermore altered their lives and consequently influenced their view of transplantation.

The transplant process and hospital admission conveyed a feeling of being in a cocoon. This was revealed through the physical and psychosocial transformations happening to the patient and family members at that time. The beginning of the metamorphosis began when the patient was offered the option of transplantation. This treatment option offered hope to the patient and family members. As the transplant countdown commenced, the patient and family members were in a relatively good physical, psychological, psychosocial condition. As this patient reflected on her physical condition pre-transplant:

I mean I had started feeling better physically because I wasn't in treatment anymore, like the radiation was really hard to go through. So I had started feeling better and stronger and my body was recovering which is why I was eligible. (P001, lines 330 to 334)

As the side effects of the conditioning regimen manifested themselves, the patients and family members noticed its physical and psychosocial consequences. Although they received pre-transplant education, they were still shocked by the gravity and severity of this medical intervention. As this patient conveys her reaction to the transplant:

I was really lucky to offered a stem cell transplant, and that day was amazing and terrifying all at once, cause I knew it was risky, yeah it would be risky but so that's it for the transplant.(P001, lines 112 to 115)

So that was already on the table and it was terrifying to hear about the transplant cause I knew how risky it was and but at the same time I knew that was it, like it's time to just get focused mentally and just think positive and to stay as healthy as I could until the transplant (P001, lines 273 to 278)

This realization regarding the gravity and severity of transplantation evoked mixed emotional reactions and fears for some patients and family members, as this husband states:

I mean and, and it was scary because this was a serious transplant it wasn't something that was just a get your tonsils out right. (P003, lines 338 to 340)

As the days elapsed following the start of the countdown for the transplant, the patient and family members discerned a progressive decline in the patient's energy levels and interaction with their social environment. This change in their activity was noticeable to participants as the patient increasingly slept throughout the day and interacted less with family members and visitors. The recipient's transformations were experienced in tandem with family members. This activity change served as a reminder regarding the severity and gravity of the transplant:

...I always made sure I brought the newspapers, so that kind of helped her through the breakfast time while she had the strength and then she'd have to lay down and that, that also brought a realization to me how sick she was cause she was not a person to lay down, she hated laying down, I mean she was active from morning till night and she couldn't sit still and you know and when she you know when she said she was tired and she had to lay down I knew she was tired, yeah and she wasn't feeling well, cause she's not one to complain about pain or not feeling good...(P003, lines 937 to 946)

The decrease social interaction and changes in the patient's behavior further conveyed this sense of being in a cocoon. These changes in behavior such as the decreased activity, low energy, fatigue, increased sleeping, and introversion are characteristics of a "dormant state". During the "dormant state", this patient focused on her health and a positive surrounding:

I mean that period to me was very much like I felt like I was in a cocoon, like I was just trying to focus a lot on staying healthy and staying happy and, and my health and I felt very focused on everything (P001, lines 394-397).

As the recipients were in a "dormant state", family members continued to visit at the hospital and experienced their "dormant state". Although the patient's interacted less with family members, they continued to spend time at the bedside frequently not communicating with the patient. The changes in the patient's activity level directly impacted family members' activity levels. Family members found themselves sleeping more frequently and entertaining themselves with more solitary activities (reading books, playing cards, etc.) while visiting the stem cell recipient in hospital. This phase allowed the patient and family members to focus on rebuilding themselves and patient for in hope for a life of new beginnings.

Rebuilding the physical aspect of the patient during the cocoon phase entailed the body healing itself. This was achieved by eradicating the cancer and the engraftment of the stem cells. It is during this "dormant period" that the engraftment of the stem cells

would happen and consequently the patient regained a new functioning immune system. Other components of rebuilding the body included the patient regaining their energy levels, being less fatigue, and sleeping less. This allowed the patient and family members to eventually emerge outside the protected walls of the transplant unit into their life of new beginnings.

The other facet of rebuilding the body during the cocoon, focused on the patient's psychosocial well-being. This undertaking was attempted by the patient and family members. As the patient focused on his/her health and the importance of a positive environment, family members also increased their focus on the transplant patient. Family members increased their focus on the recipient's needs and well-being in an attempt to facilitate their transition through this phase of transplantation. This increase devotion of time and energy towards the patient was an attempt to alleviate their burden. This alleviation permitted them to concentrate on getting better and leaving the transplant unit to start a life of new beginnings.

This emphasis gained prominence as their acuity increased, energy levels decreased, and complications manifested themselves. As the focus shifted to the needs and well-being of the patient, they inadvertently diminished their interactions with other family members and friends. They physically were present but mentally they were preoccupied with the transplant patient:

But again my spouse was you know, is the person really, the only person that fully understands because anybody that's there with you to go through it is the only person that really understands right. (P002, lines 863 to 866)

This dedication of time required a reorganization of daily activities according to the patient needs. This accent on the patient was of upmost importance. Family

members purposefully and inadvertently isolate themselves on the protected unit from the rest of the outside world, other family members, friends, and acquaintances.

The inpatient unit was a haven, a place of safety, security, protection for the patient and family members. The participants trusted the staff with regards to the care of the transplant patient. This feeling of trust alleviated their fears and anxieties regarding the well-being of the patient fully knowing that he/she being cared and supervised by qualified healthcare professionals. This trusting relationship in the medical and nursing professionals was fragile as this mother experienced and if breached caused significant distress:

Um well one thing that sticks out for me is the fact that when she did have her transplant, the night of, we happened not to stay overnight and I think that night was a pretty rough night cause when we got back early in the morning it seemed like she had intensive care around her all evening, and I asked the nurse attending, cause they said that her blood pressure had been very very very low all night.

And so I guess in my eyes she was on the brink of maybe not making it through that night.

So I asked the nurse at what point do you phone a parent or a significant other when there is that real precarious time. And she said well to tell you the truth we can't, I couldn't even leave the room and we had to be by her side all, all through the night. And I thought well that's a little bit odd because wouldn't you have a communication system between the room and the, the front unit so that if you needed something or if you wanted to communicate you could do so, supposing you needed extra help or there must, there must have been so, to me I didn't question further, there must have been a system where you could do that and in which case I'd tell somebody you know to call the parents or.

And I felt that at that time and "B" felt too perhaps we should have been there and perhaps she wasn't in the mind to tell us, tell that, but I don't know but that was really frustrating I thought cause and maybe we made the wrong call in not staying all night right after the transplant, but that's what we had done and I thought oh my god you know when, when do we, when can we go home and when can we not go home, when, when is it time when we should be here, is someone going to call us if, if you know there's a need to be called. (P002, lines 567 to 606)

As the days after transplant elapsed and the stem cells began to engraft, the patient began to feel better. This meant the patient felt less fatigued, their energy levels improved and they began to interact with family members and visitors. These changes in the patient's status were noticeable to family members, recalling that "life was coming back into the patient". These improvements in the recipient's condition evoke feelings of happiness and hope for the future and consequently diminished and relieved some anxiety. The patients and family members were emerging from their "dormant state", thus "*awakening from the cocoon*".

These improvements in the transplant recipient's condition shifted the focus of the patient and family members from the patient's well-being and health to getting discharged from the transplant unit and beyond the isolation doors that had provided protection from the outside. First, getting discharged from the transplant unit allowed them to return home, get back to a normal life, and plan for the future post HSCT. Second, patients and family members were able to reconnect with individuals and resume daily activities that were neglected throughout this experience. This permitted them to emerge from the transplant and reconnect with the world outside. This experience meant they overcame this hurdle and were now able emerge in the outside world to begin a life of new beginnings.

Relating their transition through 100 days post HSCT as an "*awakening from the cocoon*" became evident as family members shared their experiences. Three themes emerged from the data depicting their "*awakening from the cocoon*": (1) The disruptions; (2) The chrysalis; and (3) New beginnings. The disruptions were experienced as the participants entered the cocoon. While the chrysalis reflects a period of time in which

interventions were focused on the patient's care and well being in order to facilitate their transition into a new beginning. As the patient and family members came out of the transplant, they emerged into a life post cancer and post HSCT. Each of these themes is supported by sub-themes (See Table 4.2).

Themes

The narratives from the patient and family members' experiences, yielded rich data that is summarized in the following themes and sub-themes identified in Table 4.1.

Table 4.1

Family member themes and sub-themes transitioning through SCT

Essence	Themes	Sub-themes
	The disruptions	<ul style="list-style-type: none"> • Loss of body image • Loss of control • Loss of a normal life • Death around the corner
Awakening from the cocoon	The chrysalis	<ul style="list-style-type: none"> • Becoming an actor • Focus on the positive • The numbers game
	New beginnings	<ul style="list-style-type: none"> • New birth • New philosophy

The disruptions. From the onset of their discourse, stem cell recipients and their family members described their experience in relation to numerous disruptions that had transpired throughout the continuum. The types of disruptions varied according to participants; however this theme was evident in all their narratives. Participants recalled

that the moment of diagnosis represented the start of the disruptions that transpired throughout the cancer continuum and HSCT. For the patient, these disruptions had commenced prior to the cancer diagnosis as she described her abandonment of activities prior to the diagnosis related to the underlying cancer:

I guess I grew up in a normal household you know one sister, two parents and was very active, was cross country skiing um a lot and in sports like soccer, I played piano all the time, in high school I switched to playing Obo, I stopped skiing in junior high, was too tired anymore and that's when I first developed symptoms even though I didn't know they were symptoms yet. (P001, lines 25 to 31)

The disruptions were experienced in tandem and psychologically coped with. Some disruptions would “ebb and flow” and resurfaced when the HSCT was proffered to the patient. As the transplant recipient and family members entered the cocoon they experienced multiple disruptions in relation to a loss of body image, loss of control, a loss of a normal life, and death around the corner.

Loss of body image. As the patient and family members conveyed their experience, they divulged an ongoing pensiveness regarding the patient's physical changes in the course of the transplant. These changes were comprised of the following: hair loss, weight loss, muscle mass loss, swelling, changes to skin pigment and texture, changes to teeth color and rashes resulting from infections, medication reactions, and/or GVHD. The alterations to the patient's body image were not always a result of treatment related side effects.

For one family, the source of anxiety and distress was the implant device used for chemotherapy administration. The intrathecal implant device on the patient's head conjured a feeling of self-consciousness and a source of distress. This caused the patient

to hide or cover the device while out in public or interacting with other individuals as his wife recalled:

And then too he had that um my kids called it a horn (chuckle) he had that uh oh I can't even think what it called to get the intrathecal chemo. He had that so and I know he was self-conscious of that, he didn't like that, he didn't like people seeing that, so he liked to wear a hat and kind of hide it. (P004, lines 384 to 396)

The intensity/severity of these physical changes varied according to patients and was a source of anxiety and distress for the participants. For the patient, these changes in physical appearance evoked negative and positive emotional reactions:

My body was not there, like it wasn't me. My mind was gone like with all the drugs and all the chemo, I mean the chemo has still affected my short and long-term memory I'm pretty sure. I felt dumb, I felt ugly, but at the same time my spirit, I kind of connected with, with how strong I was as a person and at the same time I felt beautiful on the inside and more full of life and happier than I had ever been, it was a strange dichotomy I guess..(P001, lines 283 to 290)

As these physical changes manifested themselves, family members observed behavioral and psychosocial changes in the transplant patient. These physical changes had a negative impact on the patient's self view as described by this mother:

And then her hair started to fall off and then she didn't even, you know after that she didn't even really look after her hair, her hair cause it was so limp and so her skin started to get you know and I could see what it was doing to her, how it was uh affecting her like uh she wasn't the same person she was. I think she was almost like ashamed of herself you know. (P005, lines 416 to 422)

Just as these the physical changes affected the patient, they consequently impacted family members. The physical changes in the recipient's body resulted in family members experiencing losses as a result of these changes. These changes in the patient's physical appearance and behavior were a source of distress for family members. This husband described his reaction towards his wife's response to her hair loss during the transplant:

It really hurt me, because I knew how much she loved her hair, and I knew that that kind of took part of her away, like it just (sigh), like I don't know how to explain it, I knew she lost part of herself. (P003, lines 1255 to 1258)

The alterations in the patient's physical appearance served as a reminder for family members about the patient's cancer. These changes in their appearance reminded family members about the gravity of the illness especially when there were changes in the patient's acuity during transplant. This mother viewed the physical changes in her daughter as a deterioration of her condition:

And I could just see that you know and I'd come home from um grocery shopping whatever, she'd be laying on the couch and I would just look at her and I could just, from day to day I could see how she was just uh deteriorating (P005, lines 182 to 185)

For this wife, her husband had been a bigger man but throughout the transplant, he lost a substantial amount of weight and muscle mass along with his hair. The baldness and weight loss for the wife was a source of distress when she looked or hugged her husband:

He said it didn't bother him, but I'll admit I didn't like it because then every time I saw him it was that reminder you know some people shave their head cause they choose that but every time I saw him bald I knew it was cause he was sick and I didn't like the bald look at all. (P004, lines 380 to 384)

what bothered me more I think was he used to be like a big strong bulky man and when he came home from the transplant he had like no, like he, when I'd hug him there was nothing to him. (P004, lines 965 to 968)

These changes in her husband's physical appearance had altered the family's security and comfort that her husband once provided and was experienced as a loss for the family:

I guess just um another thing um how would I explain it, I guess what I'm trying to say is seeing your husband you know not look the same, you know he's bald and he's weak or he's tired and that was really upsetting to see him you know and not be the man I married you know or have issues now from damage you know all this treatment. (P004, lines 348 to 353)

Loss of control. The transplant imposed restrictions on the patient's life prior to and after discharge from the hospital. These restrictions evoked feelings of losing control over their lives as this wife describes:

Yeah. Well I guess a loss of control because before when you're healthy you can come and go and do as you please and do everything you want, but then there was a loss of control because he has to stay in the hospital, he wanted to come home, he couldn't come home and, and he wanted to eat but he couldn't eat you know what he wanted to. Um just a loss of control, not being able to make his own decisions, they had to make all the decisions for him with regards to his health... (P004, lines 83 to 94)

The transplant impacted some families in regards to the patient's type of employment. The transplant forced some patients to temporarily stop working, while for others the transplant required them to change employment. This wife recalled how her husband enjoyed his work but was unable to return to his previous position within the company because of precautions. These restrictions on her husband evoke a loss of control over their lives, as the husband was the sole breadwinner for this family, as the wife was a stay at home mother. She found that of all the restrictions imposed on her husband, the inability to return to his previous position was the most disheartening:

I guess he felt the loss of control, he wanted to be at work, he wanted his life back, to have normalcy but he couldn't go back to work. That one really bothered him I know. (P004, lines 83 to 94)

The patient's medical appointments after discharge from the hospital were a source of distress for family members. The patients visited the outpatient unit for regularly scheduled follow-up visits with their doctor or nurse at least a couple of times per week depending on their medical condition. These visits created feelings of uncertainty for the patient and family members. When the patient came for his scheduled medical appointment, the length of their stay was frequently uncertain. The length of the

stay would vary according to the patient's complications, assessments, and results from diagnostic test. This resulted in medical visit that lasted an entire day for the patient and family members. This meant the patient and family member spend the entire day at the outpatient unit. Patients and family members described, they would come in the morning for bloodwork and have to wait for the results. Then when the results returned, the patient would spend the entire day at the outpatient unit receiving a blood transfusion. These visits were a source of uncertainty and anxiety for patients and family members because they postponed or cancelled any events planned for that day. As the patient and family members became more familiar with the routine, they would automatically cancel events on days they were going to the outpatient unit. Patients and family found their lives were controlled and scheduled according to the needs of outpatient unit, as this patient summarizes her experience:

Like CancerCare's telling you well you need to do this and you need to do that and you can't do this and you can't do that. (P004, lines 220 to 224)

One patient had negative feelings regarding his visits to the outpatient unit after being discharged from the hospital. He was reluctant to go to the clinic because of the uncertainty regarding wait times. This wife relayed her husband's frustration with his visits to the outpatient unit:

So like I said when he went there they were wonderful, so I think that's the only complaint that he had was why do I have to go back, and or then he'd go there to get a blood test and then he'd be there for five hours cause then all of a sudden you find out he needed a platelet transfusion, so he wasn't, he was just frustrated, not with them but just frustrated with the process you know (P004, lines 140 to 146)

However, he did understand the importance of these follow visits. His wife found it frustrating because he wouldn't express his desire and negative feelings to the medical

staff at the clinic. He would vent these feelings and opinions to his wife who found it exasperating. She found herself frequently having to coerce her husband to attend his regular follow-up visits. Even though patients and family members had negative feelings regarding the outpatient clinic, they did enjoy the pleasant atmosphere.

Loss of a normal life. The HSCT meant an abrupt interruption and loss of a normal life for the participants. This meant holidays were interrupted indefinitely, certain milestones, routines and activities were temporarily stopped till the patient recovered from the HSCT. Participants described how the lives of individuals surrounding them continued uninterrupted and how theirs was halted:

Um and I guess just another thing I felt, I don't want to cry but just the sadness that you know our life was, like everybody was living a normal life and you know talking about travelling and you know buying things and going places and just the sadness that our life was kind of at a halt (P004, lines 245 to 249)

The loss of income and financial security impacted the lives of the participants. This was a source of worry for families:

I wanted to get new furniture, I didn't want to spend money, you know I was scared to spend money (P004, lines 250 to 252)

The HSCT for one patient resulted in an interruption in a milestone. Usually a pregnancy is a time of happiness for individuals. However, when the transplant was offered to the patient, she had just found out she was pregnant. This patient had to have an abortion prior to the transplant:

And I was actually, this always escapes my mind but it's probably the most important thing I was pregnant right before my transplant was offered, so I had to have an abortion which was another hard thing (P001, lines 351 to 354)

Death around the corner. Death and mortality were seldom discussed or reflected upon prior to the cancer diagnosis and HSCT. This elicited an awareness to the

fragility of life and death for the participants and reverberated on the entire family unit. Mortality and death integrated itself in the life of the patients and family members, psychosocially impacting them resulting in anxiety and distress. This wife reflects on her abrupt awareness with regards to mortality and death. She described the psychosocial impact of this realization, when her husband was diagnosed and underwent a HSCT:

Because like you know when you're in your twenties you think you're dispensable, nothing bad is going to happen and you never think it will happen to you and then all of a sudden it's like oh my god you know, cause I never thought of death before. (P004, lines 246 to 251)

This awareness created fluctuating levels of anxiety and distress related to the progression of the underlying cancer and HSCT. The participants throughout their experience reconciled themselves with this insight however it gained prominence when the haematologist offered the option of transplantation to the patient. This resurgence increased their level of anxiety and distress as this patient illustrated:

....I mean I had come to grips with death and with everything before the transplant, but it was, the transplant itself was like some immediate fear of death too, and I had to yeah it was like that kind of was, even though like all that other stuff had been a reality for me before because of all the treatment I had done. The transplant itself kind of just signified all that all over again, even though I had accepted it because you were there all the time, like everyone who came to see you saw like someone really sick and someone like dying and treated you differently... (P001, lines 75 to 84)

The offer of transplantation was a source of distress and anxiety for some family members. The survival prognosis summoned ambivalent feelings regarding the transplant. These oscillated between the possibility of extending the patient's life or hastening their death. As this mother described her reaction to the offer of transplantation:

You know it will even be worse because maybe she'll die sooner, this way I was always hoping that without a transplant she might live longer. (P005, lines 503 to 505)

So if we do this transplant and if it doesn't work that means she's gone right away, you know so this is how my mind was just always always like (snaps fingers) you know this was going through my mind continuously. (P005, lines 528 to 531)

Distress and anxiety levels varied according to the patient's changing acuity and physical appearance. These levels increased as the patient's acuity increased and treatment side effects manifested themselves (i.e. increased frequency of medical interventions, equipment at the patient's bedside, increased weakness and dependency). This served as a reminder about mortality and death for the participants. For this husband the increased frequency of medical interventions and equipment at his wife's bedside served as a reminder of her fragility:

Um just seeing how weak my wife was, to see somebody that was so healthy and vibrant and that she needed help out of the bed, you know in and out like especially by the time we got close to day zero, um when we were a negative four or five you know, you know that was extremely difficult for me to, to see and then tied to that, those pumps, uh I mean and all those lines and uh at one time you know she had I think it was like six lines or seven lines, I had taken a picture of it and uh all these lines and she had I don't know four or five pumps on that stand (P003, lines 906 to 915)

As the patient's condition improved, the prominence of death would diminish resulting in decreased levels of anxiety and distress for the participants. These improvements meant the patient would be discharged from the hospital in the near future. This was an exciting time for the patient and family members however this event was overshadowed by a fear of death. The reemergence of this fear was a consequence of the patient's immature immune system and increased susceptibility to infections. Participants believed an infection was a possible death sentence. As a result, strangers

were considered a potential source of infection especially when going out in public and created a significant amount of anxiety and distress for patients and family members.

This participant highlights her anxiety when meeting new individuals in public after being discharged from the hospital:

Mine was like a survival one every day, like every moment, like you're looking like is this person going to cough on me and be sick and I'm going to die, or like (P001, lines 727 to 729)

In light of this fear of infection, they isolated themselves from strangers and restricted their excursions in order to minimize their likeliness of developing or transmitting an infection depicting another method of cocooning. The heightened awareness to the recipient's susceptibility to infections and precautions instilled a feeling of being in a cocoon for family members.

Death and mortality was a matter of considerable momentousness in the life of this patient. This thought psychosocially impacted her throughout her experience. Through introspection and reflection, this patient was able to reconcile herself with her own mortality and fear of death:

....I remember just preparing for death a lot, like I remember sitting out on my balcony right behind us and just trying to figure out what it would be like to die. I mean it was a lot of, of facing death at that time...(P001, lines 307 to 313)

I mean I was raised Catholic, I don't know if I believe in God (inaudible). I'm not religious anymore but facing death, my friend told me death is whatever you want it to be, so the thought of death for me was to go camping (chuckle). Like I would just, if I die, if nothing happens, then nothing happens.... (P001, lines 650 to 655)

This consciousness and fear of death did not always have a negative connotation. For some, this awareness had a positive impact on their relationships. Some families settled past differences and accordingly brought the family closer together. This wife

recounts how her marriage became closer because of death illustrating another form of cocooning:

..it did bring our marriage closer because you know death was on our mind.(P004, lines 124 to 125)

These multiple losses were experienced as the patients and family members entered the cocoon. Family members would focus on the patient in an attempt to minimize the ramifications of these losses in order to facilitate their transition through transplantation. This is observed as the participants described how the recipient's needs and well-being became the central focus in the family's life in the chrysalis.

The chrysalis. The stories related by the research participants highlighted a stage in their experiences where the cancer and transplant dominated their lives. Actions and interventions implemented by the recipients and family members were to facilitate a sheltered environment thus providing an opportunity to grow and transition in their life of new beginnings.

The ramifications of the medical treatments became more eminent as the patient's acuity changed and as the cancer treatments and HSCT progressed. From the onset of diagnosis, patient and family members recall how this became the primary and central focus in their lives. This husband summarized his experience with his wife's illness and the HSCT, highlighting a focus on her medical care:

.. then for two and a half years that's all my life and her life was, was just doctors and nurses and hospitals and beds (P003 Lines 120 to 126).

The HSCT involved frequent visits to the inpatient and outpatient units for doctor's appointments, chemotherapy/radiation treatments, and hospital admissions. The frequency of these visits required a substantial amount of time to be committed to their

care. Family members devoted this time to the patient's care and well-being in an attempt to facilitate their transition to a life of new beginnings.

At a point throughout their experience, the patient required a hospital admission for the HSCT to the isolation unit. This hospitalization provided a protected environment like a chrysalis. This hospitalization meant the patient was away from his or her family for an extended period of time. As a result, a substantial amount time was spent on the unit which became an extension of the home. The length of the family members stays varied according to families, commitments and family obligations frequently requiring a reorganization of daily activities (i.e. running errands, appointments, getting children ready for school, etc...). This husband stayed with his wife at the hospital only leaving for brief periods:

I just lived at the hospital, I never left there, well no I wouldn't say that, I left long enough to come home and have a shower and go back. At that time we had rented an apartment here in Winnipeg cause we weren't from Winnipeg (P003, lines 188 to 191)

This rural family moved within the city boundaries for part of his wife's cancer treatments and the whole HSCT. In the beginning, they would travel to the city for his wife's appointments however when the frequency of medical visits and travel costs increased they decided to rent an apartment in the city. When this family travelled for care, they found that their time was spent on the road and in hotels. This mother described how she relocated to the city with her daughter and son-in-law for the cancer treatments and HSCT:

And um and then like, like it just got worse and worse with her sickness and well I, I just I moved, so they moved to the city because she had so many doctor appointments with, with Health Science. They lived in [name's town] of course and then she moved to, they moved to the city, found an apartment and I moved

with them because uh I didn't want her to be alone with "R" worked or, uh so she needed me and I just wanted to be with her all the time. (P005, lines 116 to 127)

Families with children found it difficult to spend time at the hospital because of competing demands, thus experiencing another type of cocooning. Healthy family members had to take care of the children and other demands prior to spending time with the patient. This wife of two teenage children at home and was unable to spend all her time at the hospital. Given this, she talked about coordinating her activities to maximize the amount of time she spent with her hospitalized husband:

Like you can leave him alone for a little bit but you can't leave him alone too long. So what I would like to do is I would like to go see my husband in the daytime while he was at school. (P004, lines 847 to 850)

Whenever possible families would ensure that someone was with the patient at all times throughout the transplant, resulting in the creation of a visiting schedule. This patient's mother moved in with the husband, ensuring a family member's presence for the majority of her hospitalization:

So then when "R" would come I would stay a little bit, when, when "R" was, was with her, we all three of us would probably try and have supper together and then I would catch the bus and I would go back to the apartment. (P005, lines 918 to 921)

A visiting schedule alleviated some stress for caregivers permitting them to strategically be away from the unit in order to tend to other demands (appointments, errands, etc...). These absences were coordinated according to medical rounds, treatments, and appointments.

When they returned home from visiting at the hospital, they were still focused on the patient frequently looking after commitments, preparing meals, and washing clothing for the patient. Others would be communicating updates to friends and acquaintances.

This mother shared her experience about providing other care activities when she returned home:

And I would always try and make her some soup, she always like homemade soup and I liked, I'd try and make her some homemade stuff that she liked. And during the night and in the evenings I would make her stuff and I would bring it to her uh in the morning so she would eat a little bit better. (P005, lines 931 to 933)

The transplant and the patient preoccupied family members and became a focal point in their lives. This dominated their interactions with individuals and other family members as this wife describes:

You, it's funny if, I found myself and I had to stop myself even with my twenty-one year old, like I was so focused on "R" and everything we needed to do to make this work and be a success. I found that was such a focus on my life, like I ate and breathed that, you know what I mean. Like if I talked to people I didn't really talk about anything except for "R" and what we needed to do or what we were going through, so yeah like that was my whole life, yeah. (P004, lines 1503 to 1510)

This period of time focused on the patient, the chrysalis, reflects how the family's life and energies were harnessed for the well-being and health of the recipient. The chrysalis is observed by interventions that attempted to create a positive environment in order to facilitate their transition to a new beginning: becoming an actor, focus on the positive, and the numbers game.

Becoming an actor. Recipients and family members developed an acting adeptness throughout their transplant experience. The acting developed as a result of the need to shelter each other from negative experiences. They believed negative experiences would hamper their progress throughout transplantation. Therefore the acting shielded each other from negative experiences and facilitated their progress and growth throughout the transplant experience. Throughout the interviews they recalled how the HSCT was an exceptionally emotional time compared to their previous

experiences. The mixed emotions arouse in virtue of the considerable burden associated with the life and death consequences of transplantation. As this husband explains the cluster of emotions associated with the transplant:

...you know what I think, you know what I think just a mixed bag of emotions from being scared, happy, sad, uh just a little bit of everything... (P003, lines 310 to 313)

Fears and anxieties were present throughout the transplant however on the day of transplantation, fears regarding its effectiveness aroused for one mother. These fears were regarding the efficacy of the preparative regimen:

...but I still at the back I was thinking did they get all the, all those bad cells you know. (P005, lines 563 to 564)

During this extremely emotional day, patients and family members did reveal a gratefulness and appreciativeness regarding the donor. One wife described how she and her husband attempted to see if any donor information such as country of origin and sex were visible. This wife described her feelings regarding the donor's act:

...but I guess the overwhelming feeling was of just the gratefulness, the appreciative that, and then also not only that that this donor did it but how, just all the people that had to pull together to pull it off you know, the nurses and whoever did it and wherever this person (P004, lines 810 to 814)

One mother talked about her vacillating emotions and internal struggle when looking at her daughter. She talked about feeling torn inside because of seeing her child suffer:

. Well it's all very heartbreaking because its, its, you know you know it's a bad for, for good but it still seeing that patient and that's not saying positive things, but the feeling is that you're, you're just being torn you know because you see this person, your child suffering and suffering in the hope of getting better, but its, you try and maintain a, a level of sort of uh, what's the word, positiveness around her because you don't want to you know you want her to feel better but at the same time you're feeling torn, you know there's an underlying sick feeling that this

person is so sick still and is it going to get better. So I guess it's mixed, very very very mixed emotions, very mixed emotions.(P002, lines 525 to 537)

Although family members experienced mixed emotions, they were concealed in the presence of the patients, friends and amongst each other. Family members would conceal their emotions to protect the patient and not scare them:

like it's hard when you're the caregiver because you don't want to scare your husband and you don't want to sound negative but there's things you want to know, so sometimes (P004, lines 307 to 310)

This masking of emotions was at times requested by the patient as this husband elucidated:

...three o'clock in the morning she had hollered and I got up and she had to go to the bathroom really bad but she didn't have enough time to, to get herself some morphine and for it to, to act hey, so she had to go, so you know I got her on that walker and got her over there and she was in so much pain when she finally got there and I just, I just started crying and I just lost it, I just didn't hold it in, and she just, like just so sharp and she just said, stop, stop doing that, and right from there it was just like, that's just when it really hit me and I remember so many emotions, never talked about it after that, never said anything, neither her mom and just that if this is how she wanted to deal with it then that's, that's what we were going to do, and that's what we did so... (P003, lines 191 to 204)

One mother described the concealment as a game with both individuals fully knowing what was happening yet not discussing the issues:

We were sort of like playing games with each other, you know knowing it was going to happen but yet not admitting it to each other. (P005, lines 271 to 274)

This concealment was not limited to emotions, but to other facets of the transplant. When family members had children, they would understate the gravity of events, complications, treatments related to the transplant. This understating by parents was to protect and reduce the psychosocial impact of transplantation on their children. This wife recalled how they downplayed the magnitude of the transplant to protect their children:

...Yeah. And you know what like not that “R” and I downplayed it but we tried to not think of it as such a big bad thing. You know what I mean like we tried to just you know, cause I guess too we didn’t want to scare our kids (P004, lines 673 to 680)

This protectionism was not limited to young children. One mother described selectively sharing information with the patient’s adult siblings in order to not burden them:

...even with my boys I wouldn’t tell them everything. Because I just didn’t want to, somehow I thought well if I don’t tell them everything it will be, it will be easier on them you know. (P005, lines 791 to 798)

Family members disguised their emotions, feelings and the patient’s condition from strangers and friends. They concealed this information because of privacy and a preconceived notion of what they thought people wanted to hear as these two mothers share:

Or even to other people like I, I’d come home you know occasionally I’d come home and of course I’d see people on the street, the first thing they would say, how is “J”, well you know alright you know which of course she wasn’t but, but I didn’t want to tell them, I pretended that you know everything is fine, why should I go and tell you then you know before you know it at coffee you go, you go and you talk about your daughter, so I was always like, even though it hurt me to say, alright, like not bad, because I knew she, she’s bad you know. (P005, lines 774 to 783)

So you know I just, instead of maybe crying to them or telling them about my fears or you know stuff, concerns, I just kind of kind of acted like everything was alright and I think people liked that too. It’s just like you know when somebody says to you how are you, they want to hear you say good, they don’t want to hear well I’m actually having a shitty day (chuckle) and then to start to you know what I mean, so that’s kind of how I did it. (P004, lines 295 to 303)

The patients also concealed information, facts, or symptoms from spouses or other family members to protect them. This was done to minimize the psychosocial repercussions of the transplant and protect family members. As this wife recollects:

Cause uh, and I don’t know why he didn’t tell me, if he didn’t want to scare me or if he kind of just didn’t even want to acknowledge that it was really happening you know. So I guess if he didn’t tell me he didn’t, he could pretend everything was okay when it wasn’t so. (P004, lines 237 to 241)

so you know this cover up was just sort of not, she thought maybe if she was as strong to the end and stuff that she wouldn't you know, it would be easier for me, so. We were sort of like playing games with each other, you know knowing it was going to happen but yet not admitting it to each other. (P005, lines 271 to 274)

Although family members concealed their emotions and information to protect the patients and other family members, this was a difficult task. The inability of family members to express themselves was frequently a source of distress and isolation. They expressed their emotions in private or in the company of selected close family members, usually the other spouse or caregiver. One family member found the only other person who could relate to her was her spouse:

Well um I guess the biggest support I has was my spouse, you know because we lived, we were the closest to the situation and we would be there often, we would be each other's support, main support (P002, lines 543 to 546)

Some family members and patients used the psychosocial support services offered at the hospital to assist them with validating their emotions and feelings as this wife describes the services her husband employed:

my husband went to a, to see some of the counsellors at CancerCare. On occasion as well, yes. So that was helpful um-hmm to just I guess too validate the feelings you have that are, are normal when you don't know if they are or not or. (P002, lines 547 to 554)

Other family members used the counseling services to assist them with marital and family issues arising from the transplant:

And then one big thing that did help me was I, and I contacted "A" because "A" um one time my husband and did go see her was when that time they wanted my husband to do this radiation. So we did go see her for counseling and we talked to her about that, and then we talked to her about a few issues we were having in the house with my twenty-one year old. (P004, lines 438 to 447)

However, one patient refused the counselling services:

my husband, he doesn't like, he doesn't really like the counselor kind of stuff. (P004, lines 445 to 447)

Focus on the positive. Family members revealed the establishment of a positive environment as pivotal during the HSCT and after discharge. Creating this positive environment and worldview was important for family members in light of the gravity of the clinical situation. This was attempted for the psychological and psychosocial well-being of the patient. They believed this would assist in minimizing psychosocial impact on the patient. Generating a positive milieu was critical as the patient's acuity and emotional well-being worsened. Family members undertook this through various methods: positive role modeling, looking at the positive aspects of situations, being upbeat, and encouraging the patient. This husband attempted to create a positive environment for his wife by writing poems and bringing gifts for her:

it was really important to put a smile on my wife's face and that's why I wrote the poems and, and I would just do little things you know of course lots of gifts of some all sorts (P003, lines 877 to 880)

This husband looked at the positive aspects when his wife's acuity changed and she was being discharged from the hospital:

I mean I remember the first time that she was, they had disconnected the pumps but she still had to stay in for a little while let but they had given us a, a night pass and, and we made such a joke, and we were such a high on there and we just told everybody we were going out on a date and this is my, my little darling and everybody got I remember such a kick out of that you know and we were, we were just like a couple of two little young lovebirds you know and we were leaving the hospital you know and all we did was basically we went straight to the apartment because she was so, so weak and so tired anyway, but it was just such a treat just to get out of that room and you know for her to get into, even the apartment even though well at that time it was a two bedroom cause her mom had spend more and more time with us so we got a two bedroom apartment so, so she had a bed, so yeah not that's, that was a phenomenal high for us, yeah it really was(P003, lines 965 to 981)

The creation of a positive environment also involved assessing relationships with family members, friends, and acquaintances. This assessment resulted on occasion in the

dissolution of relationships in order to minimize the stress and anxiety in the patient's life. The dissolution of these relationships permitted them to focus on the positive relationships in their lives and on transplant:

he actually kind of walked away from his family because he couldn't deal with all the crap (inaudible) crap and he was so focused on getting better he didn't want all the stress and anxiety, so he had to walk away from his family. (P004, lines 619 to 622)

The numbers game. Participants affiliated an importance to the daily laboratory results (white blood cell count, hemoglobin, platelets) that were communicated to the patient. A lot of weight was associated with these results and served as an indicator of the patient's progress and successfulness of the transplant. Family members monitored these numbers according to the explanation they received prior to the transplant. They expected a decrease in the counts after the start of chemotherapy and stem cell infusion followed by a gradual increase in the numbers. As the counts decreased, there was an underlying fear regarding the successfulness of transplantation:

No, I'm just uh (short pause) it's hard to pinpoint anything that was, I mean you know you watch those numbers and you watch the days and the first days are not so, so easy because again you don't know where, where you're going right with the counts going down right, that's what happens. (P002, lines 496 to 501)

As the counts decreased, achieved zero, the patients and family members impatiently await an increase in the counts however minute:

they had forewarned us for that, so that part we knew, I mean you know it wasn't really a surprise right, but it was after that you know, by the time the fourth, fifth day came along you were getting pretty antsy, you know when you just see these zeroes and you're were waiting for that, plus one or plus two, just so minute right. Uh you know and then that would just, like wow it was just like, we were almost like celebrating you know and we had a long way to go but I mean that, it was just that little bit, it was just like wow we're on the, on the upside right. (P003, lines 847 to 856)

This fear would be alleviated when the counts started to increase. This recovery represented a successful transplant and permitted an opportunity for enjoyment. The fear regarding the success of the transplant was not completely alleviated, there was still and underlying fear of an unsuccessful transplant:

And then (short pause) um I would say, I don't know, generally I guess the, the latter part after the counts go, start coming up again and then it's a better experience than before, but before that still you're on, you're still wondering you know. (P002, lines 505 to 509)

As the laboratory values after transplant improved, they signaled a possible discharge from the hospital. These laboratory values served as an indicator to the next phase of the transplant which was the eventual discharge from the hospital and a life of new beginnings.

New beginning. The HSCT represented for the participants an opportunity for a “new beginning”. For years prior to the transplant, the focus of the participant’s lives was the patient’s cancer treatments and hospitalizations. These years had been marked with numerous “ups and downs” related to the patient’s remission and relapse status, cancer progression and treatments. This required recurrent hospitalizations for treatments, complications, treatment side effects. These regular visits to the outpatient unit altered their lives.

The option of transplantation provided an opportunity for the patients and family members to restart their lives, which for many years had been dominated by the patient’s underlying cancer. The transplant provided and opportunity to resume old activities and routines previously abandoned due to the cancer and its side effects. This resumption of provided a sense of comfort for family members, as this mother related:

Because she was really interested in playing her music again I think that and she was told she perhaps never could play again, she started to try and you know she was able to try little by little to get back into her routine of music as well which was helpful for her to see that she get back. (P002, lines 1226 to 1230)

While this husband was comforted by the patient's return to an old routine such as going out for breakfast:

because she was able to start doing a little bit of stuff you know and we had to be very careful, you know she had to wear a mask and stuff hey and you know being out in the public, not to touch and that hey, so but I mean she was determined to go back to her restaurant and have her breakfast (P003, lines 998 to 1002)

The resurgence of activities that were incorporated in the family life before the cancer diagnosis provided a sense of comfort and security for the families. These activities or routines meant they were returning to a "normal life"

For others it meant they could return to work as some family members went on medical leave at point during the HSCT. This meant in due course they would return to work. However, some patients would have to modify their working conditions or altogether change their type of employment, as this husband related:

they were happy times you know, we were you know confident that life would almost get back to normal and we'd start talking about what we were going to do with the future now at that time you know prior we were in trucking and we had sold the truck and everything and we'd come to realize that that wasn't what was going to happen (P003, lines 1008 to 1013)

Patients and family members residing within the city were able to return home after being discharged from the hospital. The participants who resided outside the city limits had to return to their temporary accommodations in the city. These participants viewed the end the one hundred day period post HSCT as their opportunity to return home. They were counting down the days to return home:

cause all we talked about is you know a few more weeks we're going to go home right you know and, and then counting the days, like day you know sixty-five or

day seventy or whatever it is you know, cause they had told us the first hundred days was the critical part, you know once you got past a hundred days then you know, you were okay right and things were going, you know you'd kind of beaten it or made it you know and so, so which was really funny, so then you start counting those days and I did I even marked them on a calendar you know and stuff you know and yeah they were, (P003, lines 987 to 997)

Although they resided in temporary accommodations, they attempted to maintain activities and routines which provided them comfort and a sense of “normal”.

The participants discussed how after the transplant the topics of conversations changed between the patient and family members. The topics of conversation went from focusing on treatments issues to planning for the future and returning home. The options of day or overnight passes were viewed as a happier time, an opportunity to return home to a normal life:

I was just on cloud nine you know and we thought well for sure it is working, and it was working, it did work and, and then they just started going up and up and she was happier and we were happier and uh and those were the good times and then um she started feeling much better and then they started letting her go home you know and um those were the good times. Like things were happier, looked better, there was hope. (P005, lines 613 to 620)

A “new beginning” is seen through the sub-themes of *new birth*, and a *new philosophy* that emerged from patient and family member experiences.

New birth. The option of HSCT initiated the research process for the recipients and family members. As they gathered information and knowledge through various modalities: nurses, doctors, books, the internet and online support groups. As family members became knowledgeable and understood the transplant process and its related consequences, the theme of a “*new birth*” emerged:

Everything was terrifying; everything was amazing all at the same time, like you're completely vulnerable. I see a lot of parallels now that I have the baby, and like the same thing like you wait a hundred days, they wait three months before they're kind of a little bit more sturdy and stuff.(P001, lines 771 to 776)

When the patient returned home after the transplant, family members viewed this like taking a new baby home. This view emerged as a result of the increased dependency of the patient on family members for their care and their increased vulnerability regarding infections and possible complications.

This gained prominence in their lives as the HSCT progressed and the stem cell infusion date “day 0” approached. Family members viewed this day as a positive event, a reason for celebration, as this wife described:

...I was really excited, like cause I remember reading on the, the website, oh it's like your new birthday, like you know, so I remember I was excited, I wanted to do something funI'm like oh let's bring like balloons and a cake and let's get all, you know this is your new birthday (P004, lines 742 to 748)

The day of the stem cell infusion represented an important milestone in their cancer journey. In the years after the transplant, patients and family recalled and celebrated this date as a second birthday:

...that day, all those dates from the time that she, especially the day of the transplant would have been basically a new birth, and I think it would have been something we would have celebrated every year uh as a, as a new life, a new beginning for her, for me and for us (P003, Lines 1078 to 1106)

New philosophy. The transplant experience notably impacted the patient and family members. This medical treatment and its resulting effects changed their worldview. This reexamination of their worldview resulted from their own self reexamination, becoming aware of the fragility of life and surviving the transplant process. This resulted in the patient and family members modifying or changing their philosophies regarding life. Some family members reevaluated their lives and learnt to live in the moment and enjoy what life offered them:

I guess I learned just before the transplant was just to live in the moment, I would kind of just count to five and count to four, if I can count to four (P001, lines 553 to 555)

Yeah like really live every moment and appreciate everything that's there at the time you're, and try not to think of the, I mean as far, you're going to be hopeful an yes but try and take the negative thoughts away you know, cause what if, what if she's not there in a month, well yeah but now she is here (chuckle) so make that, make that your focus and make that the important part. (P002, lines 964 to 970)

Another family member revealed after the transplant, he became more spiritual and involved in the church:

And so forth you know and I've come to realize now that all you need to do is just be there, be there and just listen if they choose they want to start talking about something or when I did they were there and they listened u I imagine you know that you know went on and on and on and on and they stayed by me you know and, and now uh yeah it's done there, I've become very more active in the, in the church. I've now become a, a lot more attentive to people's hurts and pains they're going through and, and right now you know I've been helping a lot of people, not a lot, but like a small handful of people through you know through their, through their lives right now, like you know stuff they're going through without getting into too much detail. (P003, lines 467 to 479)

Chapter Summary

In summary, chapter four presented the findings that emerged from this phenomenological research study. Demographic data was provided about the patient and family members who participated in the research study. However, due to the small number of participants, a limited amount of demographic data was presented in order to maintain patient confidentiality. “Awakening from the cocoon” emerged as the essence of the patient and family members lived experience as they transitioned through one hundred days post stem cell transplant. Three major themes supporting this essence were: (1) The disruptions, (2) The chrysalis and (3) New beginnings. The subsequent chapter will provide a discussion of the findings using relevant literature.

Chapter Five: Discussion of Findings and Conclusion

Chapter five will discuss the results of this phenomenological research study examining the lived experience of patients and family members transitioning through one hundred days post stem cell transplantation. The following section will be divided into several sections to facilitate a discussion of these research findings. The chapter will begin with a discussion of the study's findings, examining the essence and supporting themes. Following this the chosen methodology and conceptual framework used to explore the research questions will be evaluated. Finally, limitations and recommendations for nursing practice, education, and research will be identified.

Discussion of Research Findings

The findings from this research study elucidate the lived experience of patients and family members transitioning through one hundred days post HSCT. These findings revealed the essence of their experience to be "*an awakening from the cocoon*" with themes and sub-themes supporting this essence. The following will explore and compare the findings of this current research paper with previous studies.

The Essence: Awakening from the Cocoon

Patients and their family members started their interviews by sharing their life stories. The interviews started with participants illustrating their family life prior to the diagnosis of cancer. This depiction of family life was the starting point of their journey. They described their transition through one hundred days post HSCT as a journey from living with disruptions to living in a chrysalis to finally experiencing new beginnings. As a result, the essence of their lived experience "*an awakening from the cocoon*" emerged from their stories.

A cocoon is frequently associated with the transition of a caterpillar to a butterfly. This transition from caterpillar to butterfly implies a metamorphosis occurred with the butterfly representing the final stage of this process (Academy of Natural Sciences Drexel University, 2012). Over the centuries, this symbol has been adopted by numerous faiths, coming to symbolize and mean resurrection, new life, and immortality for Egyptians, Greeks, and Catholics. As a Christian symbol the butterfly represents a “resurrection into a glorious new life” (Catholic Saints, 2008). The stem cell recipients and their family members viewed the HSCT as an opportunity to change their current way of living. In a study by Wilson, Eilers, Heermann, and Million (2009), spouses of HSCT recipients revealed the decision to proceed with a HSCT was founded on the need to provide a sense of hope for the future by modifying the disease’s course. This sentiment and view of a future post HSCT as an opportunity to start a new life is seen in studies examining quality of life and meanings of illness and HSCT on patients, caregivers, and families (Ferrell, Schmidt, Rhiner, & Fonbuena, 1992a; Stephens, 2005; Wilson et al., 2009) and start a new life. Autologous stem cell recipients in Stephens (2005) study described their HSCT as a “gift of new life” and felt reborn.

Prior to entering their period of metamorphosis and awakening from their cocoon into a new life post HSCT, life had been full of uncertainties and disruptions. The disruptions occurred in the participants’ personal, social and professional lives, frequently leading to numerous uncertainties and a feeling of being on a rollercoaster ride. Two participants in the current study described the start of their experience like a rollercoaster ride “that's kind of where our rollercoaster started, our ride from there” (P003). Spouses in Wilson and colleagues’ (2009) study used the metaphor of “riding a

rollercoaster” to characterize their entrance to the transplant experience. The sense of living a rollercoaster ride was compounded with their feelings of uncertainty.

The HSCT required the patients to be hospitalized on an isolation unit for an undetermined period of time. This hospitalization on a specially designed unit accentuated the sense of being in a cocoon for the patients and family members. They were isolated from the outside world in a protected unit. The admission to the specially designed unit is frequently been documented as a potential source of isolation for patients and family members. Not only are they isolated from potential sources of infection, they are isolated from their normal support systems.

As the transplant progressed, the focus of both the family members and patients was the patients’ health. The focus gained momentum when the patient became weaker and sicker as a result of the treatment regimen. As one participant described “I mean that period to me was very much life I felt I was in a cocoon, life I was just trying to focus a lot on staying healthy and staying happy” (P001). This feeling of staying healthy and happy was echoed by all the participants in the research. The sense of maintaining a positive attitude was shared by other patients and caregivers undergoing transplantation (Farsi, Nayeri, & Negarandeh, 2010; Ferrell et al., 1992a; McDowell, Titman, & Davidson, 2010; Wilson et al., 2009).

Throughout their experiences, numerous fears and anxieties were present. In order to foster this cocoon, the trust in the healthcare professionals was essential. Achieving and maintaining this trust was difficult for family members in this crucial time. As Jones and Chapman (2000) revealed, the transplant forces HSCT recipients to

negotiate trust with strangers. This trust is especially difficult to maintain when incidents occur. This delicate balance was vocalized by one family member in the current study.

As the HSCT recipient's recovered and the stem cells engrafted, the focus of care became the future. The medical improvements in the HSCT recipient provided hope for the future and switched the topic of conversation from the day to day, to the future. The families were now looking at new life beyond the isolation doors of the unit. The families could now plan for their new life. They emerged out of transplantation changed. Their experience with mortality and imminent death changed the families' outlooks and perspectives on life. They emerged from their experience with a new lease on life.

Themes

The following will discuss the three themes supporting the essence of the patients and family members' transitioning experience through one hundred day post HSCT. The themes that emerged from their lived experience were: the disruptions, the chrysalis, and new beginnings.

The disruptions. The transplant significantly impacted the lives of the stem cell recipients and their family members creating numerous disruptions in their normal way of being. They described how the transplant affected them in their education, employment, social activities, holiday plans, family routines and roles, etc. Disrupted family life was a theme which emerged in a qualitative study by Wu and colleagues' (2005) exploring the experiences of eleven parents of children younger than 18 years during HSCT in germ-free isolation. These parents identified two aspects of family life that were disrupted: family living style and financial burden

Literature exploring the consequences of stem cell transplantation has documented the numerous disruptions occurring to stem cell recipients and their family members. These disruptions have been in the areas of family roles (Bishop, 2009; Fife et al., 2009; Wu et al., 2005), social relations (Andrykowski et al., 1999; Bishop, 2009; Foxall & Gaston-Johansson, 1996), employment (Bishop, 2009), financial (Bishop, 2009; Fife et al., 2009; Foxall & Gaston-Johansson, 1996; Stetz, 1987; Wu et al., 2005). These disruptions may adversely affect the stem cell recipients' and their family members' quality of life during the acute phase of transplantation and post-HSCT.

Loss of body image. As a result of the treatment regimen for the stem cell transplant, the recipients experienced numerous changes to their physical appearance such as hair loss, rashes, muscle loss, weight loss, and so on. These changes to the recipients' physical appearances impacted both the recipients and family members. These changes in physical appearance were a continual stressor not only for the recipients but also for family members. Literature has highlighted that stem cell recipients' changes in physical appearance are a distressing event for both the recipients and caregivers (Baker, Zabora et al., 1999; Heinonen et al., 2005; Jones & Chapman, 2000; Russell, Harcourt, Henderson, & Marks, 2011). These changes in the recipients' physical appearance throughout transplantation have psychological and psychosocial ramifications on patients and family members. Participants revealed these physical changes to be daunting and a continual reminder of the gravity of the clinical condition. As one participant reinforced in Russell and colleagues' study (2011) appearance changes were "distressing because they reminded him that he was seriously ill and could not change this" (p. 319). These findings have been found to be supported in a study by Jones and

Chapman (2000) examining the lived experience of seven people treated with autologous bone marrow or peripheral blood stem cells. They revealed their physical changes to be “not only frightening but also a constant reminder of how ill they were feeling” (p. 156). The participants in the same study identified their physical changes as the most difficult to cope with.

The effects of these physical changes may be discerned in recipients for months post-HSCT. A study by Baker and colleagues (1999) interviewed eighty four recipients at three points post HSCT. One third of the survivors expressed concerns about their physical appearance describing themselves as physically damaged and having a worse body image at three, six and twelve months post HSCT. These changes in the patients’ physical appearance may impact the patients’ social interactions. However, participants in Russell and colleagues’ (2011) study felt the altered physical appearance had not affected their social situation because the majority of their changes occurred while they were hospitalized. This view of unaffected social interactions was not conveyed by the participants in the current study. The changes in physical appearance affected their social interactions. The patients and family members’ social interactions were affected because the length of their stay in the hospital was short. The patients and family members returned home soon after their HSCT.

Loss of control. The transplant experience evoked feelings of losing control over one’s life, that someone else was in-charge of the participants’ lives. Participants described how precautions, restrictions, and obligations with regards to medical care were of primary importance in their lives and dictated family priorities. A study by Fife and colleagues (2009) examined 192 family caregivers of autologous and allogeneic

transplant recipients reported a decreased personal control as one of three predictors of higher emotional distress for caregivers. Families described how these precautions, restrictions, and obligations were imposed on them without their input or consultation regardless of its impact on their lives. This loss of control resulted in a significant amount of uncertainty in their lives as they were unable to plan for anything. Uncertainty emerged in a study by Wilson and colleagues (2009) who described the experience of spouses of HSCT recipients. Participants struggled with the notion of control throughout their transplant experience. Other people trying to control the HSCT recipients' life was an issue for the informants in a study by Baker and colleagues (1999), highlighting the frustrations of the participants in the current study.

Wilson and colleagues (2009) identified methods by which these spouses mitigated the effects of uncertainty during transplantation by envisioning a future beyond transplantation, developing a positive perspective and instituting rituals. In the current study, one family attempted to maintain rituals during their transplant experience by having meals together at home or the hospital, going for walks in the evening or going to their favorite cafe for their morning coffee and paper. A study of parents of children with leukemia spoke about the importance and difficulty of maintaining normalcy for their families (McGrath, 2001). These rituals promoted a sense of comfort for them and a link to their life prior to transplantation, as these were habits from that period of time.

Loss of a normal life. The participants described their awakening to a new foreign world, the world of transplant while leaving behind a familiar, certain and comfortable world they had known their entire lives. Prior to the transplant, the participants described how they had plans, goals, and aspirations for the future such as

motherhood, holidays, university, and career opportunities. When they received the cancer diagnosis and the option of transplantation, these were immediately shelved indefinitely, thus interrupting their normal way of being. One stem cell recipient in Stephens' (2005) study described her grief and bereavement as "losing her life as it was" (p. 213). These events were on hold till the stem cell recipients' medical outlook was more certain, creating uncertainty and accentuating the feeling of a rollercoaster ride (Wilson et al., 2009). The participants were grieving the loss of their normal life, a life without cancer and transplantation.

The participants described how the transplant resulted in numerous activities being halted. One family member in the study described how her husband received disability benefits during the course of transplantation. As a result, the wife described how purchasing a new sofa for their home was no longer a priority because of the transplant, uncertainty, and finances. Financial concerns often arise for families undergoing a HSCT (Baker et al., 1999; Ferrell et al., 1992a; Foxall & Gaston-Johansson, 1996).

The feeling of loss regarding their past life for the participants would be emphasized when they observed other "normal" people who were not affected by cancer. Participants described how these feelings of loss would surface or come to light when they observed family, friends, and strangers experiencing birthdays, planning weddings, planning winter, and summer holidays. Observing people experiencing these events evoked sentiments of sadness and loss of what their lives could be or of been and highlighted the fact that their lives were different from the rest of the "normal" world.

McDowell and colleagues' (2010) study highlights how families were missing out on normal family life.

Death around the corner. The transplant meant families were faced with their own mortality. Previously, the concept of death was foreign to the participants prior to the cancer diagnosis and transplant, and was considered an event that occurred to others. The participants were already sensitized to their own mortality as they approached the transplant. This consciousness to mortality and possible death of a loved one was expressed in a study by Mellon (2002) examining the meaning of illness on cancer survivors and their family members. These informants expressed shock and disbelief at time of diagnosis. These expressions of shock and devastation echo the feelings of the participants in the current study.

The participants' fear of death and awareness to their own mortality did not subside as cancer treatments progressed and the option of transplantation was offered to the patient. The HSCT aroused their consciousness to the possibilities of life and imminent death because this medical procedure was to prolong their lives while at the same time possibly causing death. This consciousness is echoed in literature examining the impact of HSCT on caregivers and family members (Baker et al., 1999; Heinonen et al., 2005; Jones & Chapman, 2000; Rivera, 1997; Stephens, 2005). A family in Rivera's (1997) study revealed the SCT made them more aware of their mortality, echoing findings from a study of Jones and Chapman (2000). The fear and anxiety surrounding death are sometimes synonymous with the fear of recurrence (Bishop, 2009; Rivera, 1997; Stephen, 2005) and infection (Lesko, 1994).

The participants spoke of how their relationship with family members and partners became closer as a result of their experience with death and mortality “it did bring our marriage closer because you know death was on our mind” (P004). This was found other studies (Farsi et al., Mellon, 2002) and significant association with psychosocial adjustment and family relationships.

The chrysalis. As the participants described their stories of transplantation, a common thread depicting a sheltered and protected environment emerged. This overarching theme of shelter substantiates the metaphor of “*the chrysalis*”. Literature defines a chrysalis as a protecting covering and is referred in society as a “sheltered state or stage of being or growth” (Merriam-Webster, 2012). The chrysalis represents all the interventions undertaken by the participants in study to promote this sheltered state. These interventions were to encourage the patients and family members through their transition. The patients and family members fostered this sheltered state to protect each other from the psychosocial and psychological ramifications of transplantation while supporting each other during this period of growth. The alleviation the psychological and psychosocial repercussions of transplantation would facilitate their transition to the “new beginnings.”

The patients and family members wanted to protect each other from various threats that were known or unknown to them. In Wilson and colleagues’ (2009) study, informal caregivers wanted to protect the stem cell recipient from possible threats, even from healthcare professionals whom they trusted. Another study by Stetz and colleagues (1996) found that caregivers wanted to protect the HSCT recipient from harm and misinformation, confirming the findings of the current study.

Becoming an actor. Transplantation caused emotional strain, anxiety, and distress for the HSCT recipients and their family members. This frequently called on recipients and family members to master their acting skills in the face of disruptions and alternating periods of fear, anxiety, and hope. The plethora of mixed emotions and reactions evoked by the transplant experience are documented in literature examining the effects of HSCT on recipients, caregivers, and families (Fife et al., 2009; Ho et al., 2002; Stephens, 2005). The participants in the current study spoke of not expressing their feelings, emotions, and reactions in light of their experiences. As one participant states “she thought maybe if she was as strong to the end and stuff that she wouldn’t you know, it would be easier for me” (P005). Mellon’s (2002) qualitative study comparing the meaning of illness and quality of life revealed that survivors and family members in the study discussed their role of supporting their loved ones and showing concern which included keeping their feelings to themselves, echoing the viewpoint the participants in this current study. This perspective of not expressing emotions, feelings, fears, and reactions may invoke more psychological symptoms. Findings have demonstrated family environments encouraging an open expression of feelings may exhibit less psychological symptoms (Ho et al., 2002; Molassiotis et al., 1997).

The participants did not express their intense feelings, emotions, and reactions to each other during the transplantation. The participants however sought psychosocial support services in order to express themselves. These services were valued by the patients and family members. The professional services allowed them to express themselves in a safe and secure environment. This permitted them to express themselves without burdening each other.

Focus on the positive. Patients and family members entered the transplant with the understanding that although this medical intervention was for treating the patients' underlying cancer and prolonging his or her life, there was a possibility of an imminent and sudden death associated with this medical procedure. The participants created a positive environment to thwart the distressing and stressful experience of transplantation. This positive environment fostered the families' growth as they transitioned through one hundred days post HSCT. The patients and family members created a positive environment by employing a couple of methods.

Patients and family members altered their perspectives on the cancer and HSCT. The participants attempted to frame circumstances in a positive context. This positive formulation of a situation was especially important when negative and/or stressful events occurred to the stem cell recipients and their family members. The reframing of events in a positive context has been documented in literature examining informal caregivers of HSCT recipients (Wilson et al., 2009), parents of child whose had a HSCT (McDowell et al., 2010), and HSCT survivors (Farsi et al., 2010; Ferrell et al., 1992a). Participants in Wilson et al.'s (2009) study described the purpose of restructuring events in a positive light was a means of preventing a downward spiral. The participants in this current study attempted this intervention during negative experiences in order to maintain hope for the future, a new beginning post HSCT.

In addition to adopting a positive perspective on their experience, patients and family members fostered a positive environment through reassessing their current relationships with family, friends, and acquaintances. Relationships are an important resource and support for patients and family members during HSCT (Belec, 1992;

Bishop, 2009; Ferrell et al., 1992a; Fromm, Andrykowski, & Hunt, 1996; Ho et al., 2002; Jones & Chapman, 2000; Stephens, 2005). The valued relationships provided them hope for the future while lifting their spirits. The participants valued their ability to give and receive support. The quality of these relationships was important for patients and family members. Although they valued their relationships with family members and friends, these were scrutinized and evaluated. The quality of these relationships were examined, and if they were deemed as a source of distress, anxiety or distraction for the patients and family members, these were disbanded. Negative social supports are often a source of stress among HSCT survivors (Heinonen et al., 2005). Focusing on valued relationships caused them to be closer and more rewarding for the patients and family members (Ho et al., 2002; Stephens, 2005; Wu et al., 2005) and allowed the participants to focus on the treatment, recovery and future.

Numbers game. The daily laboratory values provided to the participants by healthcare providers was an indicator of the stem cell recipients' progress throughout transplantation. The patients and family members received an orientation to the side effects of chemotherapy and an overall description of their course of treatment prior to the hospital admission. The orientation included a description of the laboratory values that were closely monitored (white blood cell count, hemoglobin, platelets) along with changes to be observed and expected. The laboratory values were indicators of the transplant's trajectory and progress and were an important component of their daily experience. The changing laboratory values for spouses of HSCT recipients were markers of the transplant trajectory in study by Wilson and colleagues (2009). The daily presentation of the laboratory values was a method of communication between the

healthcare providers and participants. Communication between care providers, patients, and their family members is essential for reducing families' anxieties and distress (Griffiths, 2005; Mellons, 2002; Williams, 2007; Wochna, 1996).

The values were closely observed and monitored by the participants and compared to the expected outcomes. When the laboratory values coincided with the expected changes, participants felt relieved and anxieties decreased. These results reaffirmed the transplant was progressing well and according to the projected treatment plan. These laboratory results provided an objective indicator of the transplant's status for these participants. However, when the results did not correspond to the expected outcomes, this resulted in a significant source of distress for the recipients and their family members. The laboratory values would be scrutinized by the patients and their family members leading to more questions, anxieties, and distress. Shuster, Steeves, Onega, and Richardson (1996) study examined the coping patterns of bone marrow transplant patients and revealed that their informants would try not to think about things (e.g. why their counts were not coming back as they should). This coping pattern described in Shuster and colleagues' (1996) study was not shared by the participants in this current study. The emotional and psychological ramifications from receiving unexpected results highlight the importance of maintaining an open line of communication between healthcare professionals and families.

New beginnings. Family life prior to HSCT revolved around the underlying cancer. The participants described how life was dominated by medical appointments, doctor visits, chemotherapy, relapses, and remissions. Families lived one day at a time with no plans for the future because of the uncertainty in their lives. Families didn't

know what to expect tomorrow. Uncertainty is a theme seen in literature examining the impact of HSCT on patients and family members (Bishop, 2009; Fife et al., 2009; Rivera, 1997; Wilson et al., 2009). When the patients' medical treatment plan required transplantation, this allowed the families to change their view of the future. The years leading up to transplantation centered on the patients' care and needs, and now the HSCT allowed the families to envision a future. This permitted them to see beyond the "one day at a time" view of the future that had dominated the families for so many years. Viewing a future beyond HSCT assisted them in coping with the demands of transplantation. Forty caregivers of patients undergoing HSCT described how they grappled with an ambiguous future in a study by Williams (2007). This ambiguous future was hopeful, fearful or a combination of both. A hopeful view of the future permitted caregivers to endure difficulties, while a fearful view minimized losses and future disappointment. Overall the participants in the current study had a positive and hopeful view of their future post HSCT. A fearful view of the future was not verbalized by the participants in the current study, which is a contrast to Williams' (2007) study.

This vision of the future meant an end to medical visits, appointments, and treatments for both the HSCT recipients and their family members. This view of the future is shared in a study by Williams (2007) where caregivers viewed life post HSCT as getting back to their normal life. Families would now be able to return to life because they were given a second chance to life. The view of a second chance at life is reflected in a study by Ferrell et al. (1999) examined the meaning of quality of life for eight hundred and eighty eight bone marrow transplant survivors. One theme emerging from

their stories was a second chance was given. The HSCT recipients in the current study viewed their transplant as a “generous gift”.

New birth. When the stem cell recipients were discharged from the hospital, the participants described their return like taking a baby home. The participants recognized the patients were weakened from their transplant. This increased weakness caused patients to be dependant, causing family members to assume more caregiving activities. Studies have revealed that when patients return home, family members have to provide physical support (Foxall & Gaston-Johansson, 1996; Wilson et al., 2009) while stem cell recipients are increasingly dependent (Baker et al., 1999).

The HSCT afforded the stem cell recipient and their family members a second chance at life. The day of infusion was celebrated as a second birthday for the recipients and their family members. This view of the stem cell infusion day is echoed in a study by Stephens (2005) where HSCT survivors view time in a cyclical manner. These survivors used cycle of time related to their view of treatment, meaning it was just not a year passing from transplant.

New philosophy. Stem cell recipients and their family members in this research study revealed the transplant experience psychologically and psychosocially affected them. Their transplant experience altered their worldview, priorities, outlook, and perspectives post HSCT. Literature examining the psychosocial sequelae of transplantation frequently report that survivors and caregivers change their outlook on life and reprioritize their values post HSCT including finding greater inner strength (Bishop, 2009), reprioritizing values (Bishop, 2009; Mellon, 2002; Stephens, 2005), appreciating life (Belec, 1992; Bishop, 2009; Ferrell, Schmidt, Rhiner, Whitehead, &

Forman, 1992b), feelings of gratitude, and a renewed faith (Bishop, 2009). Mellon (2002) compared the meaning of illness and family quality of life of one hundred and twenty three cancer survivors and their family members. Their meanings of illness and family quality of life showed positive dimensions following treatment. Patients and family members appreciated the value of their lives and subsequently reprioritized what was important to them.

Life post HSCT was viewed in a more positive manner as a result of their transplant experience. The most frequently reported positive sequelae by ninety recipients post HSCT was a new philosophy and appreciation of life (Fromm et al., 1999). As a result of their transplant experience, stem cell recipients' priorities changed, frequently bringing into perspective what was important (Stephens, 2005) echoing the current participants' philosophy and priorities post HSCT. The patients and family members spoke about how their experience with transplantation had change their lives in a positive manner and were no longer sweating the small stuff.

Discussion of Chosen Methodology

This research study sought to explore and understand the lived experiences of patients and family members transitioning through one hundred days post HSCT. To attain an understanding of this unique phenomenon, only individuals who know what this experience is like were capable of answering the study's research questions. The research questions focused on the human experience of a phenomenon, thus employing a qualitative hermeneutic phenomenological approach was appropriate to facilitate this inquiry. This methodology provided the basis and structure for the creation, execution and analysis of this research study and its findings. The methods employed in

sampling, sample size determination, data collection and analysis were conceived and informed by this chosen methodology with the purpose of arriving at a detailed understanding of this unique phenomenon from an insider's perspective. As a result, the patients and family members' transition experience through one hundred days post HSCT was elucidated.

Discussion of Transition Theory

Along with van Manen's (1990) phenomenological methodology used to guide this study, Chick and Meleis' (1986) Transition Theory provided the conceptual structure for this research study. The Transition Theory has been used in a number of studies as a conceptual framework examining: aging transitions, African American women's transition to motherhood, recovery from cardiac surgery, family caregiving for patients in chemotherapy, women experiences with rheumatoid arthritis, and to describe immigrant transition (Im, n. d.).

The participants in this research study described their experience with transplantation as a major life altering event, viewing it more than just a regular medical intervention, "this was a serious transplant it wasn't something that was just a get your tonsils out" (P003). Their experience through one hundred days post HSCT highlights a health and illness transition as defined by Chick and Meleis (1986). This health and illness transition superimposes other transitions these participants were experiencing during transplantation such as parenthood and parenting, financial, role, educational, occupational, relationship, and developmental. The participants' description of their transitioning experience through transplantation supports the notion of multiple

transitions occurring simultaneously or sequentially (Chick & Meleis, 1986; Meleis, et al., 2000; Schumacher & Meleis, 1994).

Transitions are often a result of change, involving a process of movement from one condition to another (Chick & Meleis, 1986; Meleis & Tragenstein, 1994; Shumacher & Meleis, 1994). As a result, transitions created changes in an individual's identity, roles, relationships, abilities, and behavior reflecting the new beginnings and philosophies of the patients and family members post HSCT. The patients and family members' transition was fostered by the support of nurses and healthcare professionals. Chick and Meleis (1986) identified the components of their nursing model: process, disconnectedness, perception, awareness, and patterns of response. These components of the nursing model are essential for the patients and family members to transition from a life of disruptions, to living in a chrysalis to a life of new beginnings. These components were necessary for the patients and family members to successfully transition through one hundred days post HSCT.

Process

The study's essence "*an awakening from the Cocoon*", supporting themes, and sub themes implied a metamorphosis occurred to the patients and family members during their one hundred days post HSCT experience. The participants' metamorphosis was initiated when the option of transplantation was proffered to the patient and family members and continued through one hundred days post HSCT. This metamorphosis involved the patients and families going through a journey, from living with losses to living in a chrysalis to finally experiencing new beginnings. The metamorphosis

experienced by the families signified a process occurred from the beginning of their experience with transplantation up to one hundred days post HSCT.

Disconnectedness

In Chick and Meleis' (1986) nursing model, disconnectedness is associated with a disruption of the linkages associated with feelings of security. The cancer diagnosis and required HSCT was a traumatic and unanticipated event in the participants' lives causing a sudden loss to their normal way of being. This unanticipated event caused disruptions in the patients and family members' lives, invoking numerous losses in their present and future lives.

Perception

Perceptions are the meanings associated to the transition event and vary according to individuals (Chick & Meleis, 1986). The participants' perception of transplantation influenced how they responded and experienced the whole process. In this current study, they viewed their experience in a positive framework, regarding the transplant as an opportunity for a new beginning, a life post HSCT.

Awareness

Chick & Meleis (1986) nursing model of transition maintains that a person experiencing a transition needs to be aware of the changes that are occurring. The patients and family members started researching their underlying disease and associated treatment modalities at diagnosis. When the option of transplantation was offered to the patient, they had an understanding of this treatment modality. Their knowledge was further enhanced when they received the transplant information binder, spoke to the hematologist, BMT nurse clinician, nurses, and other healthcare providers. Some of the

families sought a second opinion which validated their current plan of care. The stem cell recipients and their family members actively researched HSCT on the internet, seeking websites and chat rooms discussing HSCT from the perspective of healthcare providers, stem cell recipients, and caregivers. They entered the transplant aware of their options and possible complications. This awareness influenced how they responded and experienced transplantation.

Patterns of response

Patterns of response are the observable and non observable behaviors of individuals experiencing a transition (Chick & Meleis, 1986). The participants' responses to their transitioning experience varied depending on where they were with the metamorphosis.

Chick and Meleis (1986) nursing model is a dependable conceptual framework to describe the lived experience of patients and family members transitioning through one hundred days post HSCT. The nursing model's major components are all represented within the findings of the study and facilitated the understanding of families' lived experience through this phenomenon.

Research Study Limitations

The following section will acknowledge and discuss limitations associated with the current research study. The data generated by this research study presented a rich detailed account of their transitioning experience through one hundred days post HSCT. Given a qualitative phenomenological methodology and a purposive sampling technique was employed, the findings generated from this study are not meant to be generalized beyond these participants.

The study's sole stem cell recipient is a limitation. The perspective of other stem cell recipients was elucidated from their family members' detailed description of events. Having more stem cell recipients in the research study would have permitted the researcher to explore the research question: What are the similarities and differences in the meaning of the transition experience between patients who have undergone HSCT and their family?, providing greater insight into their lived experience.

The research sample was comprised of one male participant whose experience with transplantation was similar to other participants. Incorporating the perspective of other male participants would provide more insight to the family's lived experience.

All the research participants in this current study were Caucasian. Recruiting stem cell recipients and their family members from different cultural and ethnic backgrounds would provide a more heterogeneous image of transplantation.

One family (2 participants) was from a rural location, researching rural families experiencing transplantation would provide more insight to their unique experience with transplantation.

The researcher's inexperience conducting a research study is another limitation of the current study. The researcher's lack of experience was minimized through the implementation of oversight strategies like the use of field notes, repeatedly listening to the audio recordings, reviewing transcripts, and seeking the guidance of the thesis committee chair.

The findings generated from this research study provided valuable insight into the lived experience of transitioning through one hundred days post HSCT. These findings present more breath and depth to current literature examining HSCT. The study's result

provide healthcare professionals with an increase understanding of the family's lived experience through this phenomenon from an insider's perspective, adding to the current body of literature.

Recommendations

The following section will explore recommendations in order to facilitate and enhance patients and family members transition experience throughout one hundred days post HSCT. These recommendations in the areas of future nursing practice, education and research are informed from the findings of this current study.

Recommendations for Nursing Practice

Nurses are crucial in facilitating the transition of patients and family members through one hundred days post HSCT. However, nurses' knowledge and understanding about this transition experience is not always derived from the patients' and family members' perspective. This research study generated a detailed in-depth description of their transition experience, providing an everyday description of their lived experience through this phenomenon. These results can inform nurses along with other healthcare professionals about patients and family members' experiences as they transition through one hundred days post HSCT from an insider's perspective.

Facilitating their transformation during this crucial period may be achieved by recognizing the importance of supporting patients and their family members through the different phases of transplantation. Nurses are integral in facilitating the patients and family members' transformation during this crucial period of time. This may be achieved by recognizing the importance of supporting patients and family throughout all phases of the transplant trajectory. This requires a continual assessment and reassessment of

patients and family members' support systems from the moment of diagnosis through the entire transplant trajectory.

From the moment of diagnosis and throughout the transplant continuum, patients and family members experienced multiple needs. Nurses must assess and anticipate family needs on a consistent and regular basis along the transplant continuum as their needs evolve over time while taking into consideration the uniqueness of individual experiences.

The transplant experience reveals itself is an extremely emotional and distressing time for patients and family members. Nurses must support both patients and family members during this period of time. Along with supporting families, the nurses must continually assess and reassess patients and family members' emotional supports on a consistent and regular basis for all phases of transplantation. This must be integrated into the daily plan of care for nurses.

Recommendations for Nursing and Other Healthcare Professionals' Education

Nurses are often a crucial and instrumental resource for families as they steer the healthcare system. Patients and family members' view the nurses as a valuable resource during their transition experience. Nurses must be provided with the education and resources for using evidence-informed practice. By empowering nurses with the tools required to use evidence-informed practice, this will allow them to share information with other nurses, healthcare providers, and families in order to provide family centered care.

Educators need to enhance nursing students' knowledge and understanding of the transition process of patients and family members along with the need for psychosocial

support. Nursing students must be exposed to these processes and supports early in their education in order for them to understand its relevance to current nursing practice.

By exposing students to the supportive care required by families and the available resources (such as psychosocial support services), student will be well versed and able to share information and support families through this processes thus providing more holistic care.

Recommendations for Nursing Research

Findings from this research study provide insight into the transitioning experience of patients and family members through one hundred days post HSCT. However, this study does highlight areas requiring further investigation to facilitate patients and family members' transition experience throughout transplantation:

1. Further research needs to be undertaken to capture additional experiences and build on the themes from the current research study.
2. Explore the lived experience of rural patients and family members transitioning through transplantation. They provide a unique insight into this phenomenon.
3. Need to examine the barriers and facilitators of transplantation and discharge for patients and family members.
4. Explore the lived experience of patients and family members from different cultures undergoing transplantation.
5. Research the use of family interventions for families undergoing a transplant.
6. Explore the lived experiences of other BMT/SCT populations outside the province of Manitoba in order to explore similarities and differences.

The above mentioned recommendations serve to increase the current body of knowledge on families undergoing transplantation. These recommendations will provide a more comprehensive view of the transition experience through transplantation thus improving the quality of care for both patients and family members.

Conclusion

This phenomenological research study provided valuable insight and knowledge regarding the lived experience of patients and family members transitioning through one hundred days post HSCT. The research participants revealed the essence of their experience as “*an awakening from the cocoon*” while transitioning through this period. Three themes emerging from the participant’s narratives and supporting the essence: the disruptions, the chrysalis, and new beginnings were discussed in relation to other relevant research studies. The conceptual framework along with the research methodology were evaluated and presented in regards to this study. Finally, the research study’s limitations and recommendations for nursing practice, education and research were discussed.

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Appendices

- Appendix A: Approval Certificate ENREB
- Appendix B: Approval Certificate RRIC CancerCare Manitoba
- Appendix C: Approval Certificate HSC Research Impact Committee
- Appendix D: Amendment Approval Certificate ENREB
- Appendix E: Amendment Approval Certificate RRIC CancerCare Manitoba
- Appendix F: Information Letter for BMT Nurse Clinician and Post HSCT Registered Nurses
- Appendix G: Script for Meeting between Researcher and BMT Nurse Clinician and Post HSCT Registered Nurses
- Appendix H: Informed Consent for BMT Nurse Clinician and Post BMT Registered Nurses
- Appendix I: Script for Meeting between BMT Nurse Clinician or Post BMT Registered Nurses and Potential Participant (when giving Letter of Invitation)
- Appendix J: Letter of Invitation for Potential Participants
- Appendix K: Researcher's Telephone Script
- Appendix L: Informed Consent Form Stem Cell Recipient
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- Appendix N: Demographic Data Form for Stem Cell Recipient
- Appendix O: Demographic Data Form for Family Members
- Appendix P: Interview Guide for Stem Cell Recipient
- Appendix Q: Interview Guide for Family Member

Appendix A: Approval Certificate ENREB



UNIVERSITY
OF MANITOBA

Ethics
Office of the Vice-President (Research)

CTC Building
208 - 194 Dafoe Road
Winnipeg, MB R3T 2N2
Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

February 4, 2011

TO: **Daniel Gagne** (Advisor R. Woodgate)
Principal Investigator

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2010:143**
"The Lived Experience of Family Members Transitioning through 100 Days Post Allogeneic Stem Cell Transplantation"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to the Office of Research Services, fax 261-0325 - please include the name of the funding agency and your UM Project number. This must be faxed before your account can be accessed.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix B : Approval Certificate RRIC CancerCare Manitoba



CancerCare
MANITOBA
ActionCancerManitoba

February 7, 2011

Daniel Gagné

○ 675 McDermot Avenue
Winnipeg, Manitoba
Canada R3E 0V9

○ 409 Taché Avenue
Winnipeg, Manitoba
Canada R2H 2A6

www.cancercare.mb.ca

Re: RRIC #05-2011: The Lived Experience of Family Members Transitioning Through 100 Days Post Allogenic Stem Cell Transplantation

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC).

The following departments at CCMB have signed off on this study: Nursing, and Patient and Family Support Services.

According to the CCMB RRIC submission form that you completed, no CCMB paper charts will be required for this study. No assistance will be required from Cancer Registry or Epidemiology. The duration of the study will be approximately 12 months.

A copy of the signed CCMB PHIA form for research is appended to this letter.

ANY SIGNIFICANT CHANGES TO THIS RESEARCH PROJECT SHOULD BE REPORTED TO THE CHAIR FOR CONSIDERATION IN ADVANCE OF IMPLEMENTATION OF SUCH CHANGES. Significant changes include (but are not limited to): a change in the study design or in the data to be collected; a change in the study duration, the patient cohort to be studied, or the number of participants to be studied; the need to review CCMB paper charts (when not originally planned) or the need to review significantly more CCMB paper charts than originally planned; the addition of other trainees or co-investigators to the project; or the inclusion of additional individuals who will have access to the data or database.

Please cite the RRIC number for this study in all future correspondence with the RRIC about it. Please note that annual approval is not required if there are no changes to the project (as outlined above).

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,

Rochelle Yanofsky, MD FRCPC
Chair, CCMB Research Resource Impact Committee

Enclosure: Signed CCMB PHIA form for research (to Daniel Gagné only)

cc: Dr. Anne Katz – Nursing
Jill Taylor-Brown – Patient and Family Support Services
File copy

Appendix C: Approval Certificate HSC Research Impact Committee



Health Sciences Centre
Winnipeg

Office of the Director of Research

Dial Direct 204-787-4831
Fax 204-787-4547

February 10, 2011

Daniel Gagne

Dear Daniel Gagne

**RE: THE LIVED EXPERIENCE OF FAMILY MEMBERS TRANSITIONING
THROUGH 100 DAYS POST ALLOGENEIC STEM CELL TRANSPLANTATION.**

ETHICS #: E2010:143 RIC #: RI2010:232

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

A handwritten signature in cursive script, reading "Karen Shaw-Allan".

Karen Shaw-Allan
Research Protocol Officer
Health Sciences Centre

cc: Director of Research
Ancillary Services, Finance Division



Appendix D: Amendment Approval Certificate ENREB

UNIVERSITY
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Ethics
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AMENDMENT APPROVAL

May 16, 2011

TO: Daniel Gagne
Principal Investigator

FROM: Stan Straw, Chair 
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2010:143
"The Lived Experience of Family Members Transitioning
through 100 Days Post Allogeneic Stem Cell Transplantation"

This will acknowledge your Amendment Request received May 12, 2011 requesting amendment to your above-noted protocol.

Approval is given for this amendment. Any further changes to the protocol must be reported to the Human Ethics Secretariat in advance of implementation.

Appendix E: Amendment Approval Certificate RRIC CancerCare Manitoba (page 1 of 2)



APPROVED JUN 13 2011

RRIC # 05-2011

Protocol Amendment Form for studies already approved by the CancerCare Manitoba Research Resource Impact Committee (RRIC)

Instructions: Changes to the original approved RRIC application must be submitted to RRIC for review and approval in advance of their implementation. Complete each section and indicate where no change is requested. **Once the amendment has been reviewed by the RRIC Chairperson, a signed copy of this form will be returned to you with the outcome of the review outlined in section 8.0. Study amendments will be reviewed between meetings and can be submitted to the RRIC secretary at any time.**

For the amendment to your study to be reviewed, please submit four (4) copies of the following to the RRIC Secretary:

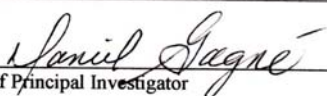
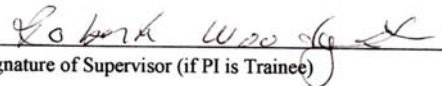
- a) the completed CCMB RRIC amendment form (attach revised PHIA form and/or Trainee Form if applicable)
- b) the most recent REB amendment submission form
- c) the REB letter approving the amendment
- d) the revised study proposal
- e) if applicable, the HIPC amendment submission form approval letter

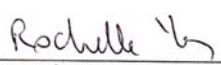
**RRIC Secretary, Jennifer Cabral, CancerCare Manitoba, Room ON5008, 675 McDermot Avenue,
Winnipeg, Manitoba R3E 0V9; Telephone: (204) 787-4170, Fax: (204) 787-2190, Email:**
Jennifer.Cabral@cancercare.mb.ca

RRIC information and forms are located on CCMB shared drive J:\Research Resource Impact Committee and CCMB website http://www.cancercare.mb.ca/home/cancer_research/rric/

1.0	Study Information: Date: May 23, 2011 Study Title: The Lived Experience of Family Members Transitioning Through 100 days Post Stem Cell Transplantation Principal Investigator: Daniel Gagné Address: 449 Sherbrook Street Phone: 204-228-0398 Fax: N/A Email: dagagne@ustboniface.mb.ca Study Coordinator: N/A Address: N/A Phone: N/A Fax: N/A Email: N/A Correspondence to be directed to: <input checked="" type="checkbox"/> Principal Investigator <input type="checkbox"/> Study Coordinator		
2.0	Change in Study Personnel: The RRIC must be notified of those individuals who will be accessing study data and a revised CCMB PHIA form for research must be submitted with this amendment. <input checked="" type="checkbox"/> NO CHANGES REQUESTED <input type="checkbox"/> CHANGES REQUESTED		
	Original List of Study Personnel (as listed on the original PHIA form)	Revised List of Study Personnel (please specify the names and roles of all individuals who will have access to study data. A Trainee form must be submitted for each trainee added to the study personnel list.)	

**Appendix E: Amendment Approval Certificate RRIC CancerCare Manitoba
(page 2 of 2)**

7.0	Signatures:			
 Signature of Principal Investigator		May 23, 2011 Date		
Daniel Gagne Printed Name of Principal Investigator				
 Signature of Supervisor (if PI is Trainee)		May 23, 2011 Date		
Dr. Roberta Woodgate Printed Name of Supervisor				

8.0	For RRIC Use Only:			
Departments Impacted by change:		Contact:	Signature:	Date:
<input type="checkbox"/> Cancer Registry		Ms Gail Noonan 787-2157		
<input type="checkbox"/> Epidemiology		Dr Jane Griffith 235-3277		
<input type="checkbox"/> Health Information/Health Records		Ms Jacqueline Sholdice 787-2266		
<input type="checkbox"/> Clinical Investigations		Ms Kathryn Dyck 787-2127		
<input type="checkbox"/> Other (specify)				
Approved: <input checked="" type="checkbox"/> Yes  Signature of RRIC Chairperson June 10, 2011 Date		Approved: <input type="checkbox"/> No Reason for not approving: <input type="checkbox"/> Requires Full Committee Review <input type="checkbox"/> Information missing Specify: <input type="checkbox"/> Other Specify:		

**Appendix F: Information Letter for BMT Nurse Clinician and
Post HSCT Registered Nurses**



Faculty of Nursing

Faculty of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7456
Fax: (204) 474-7682

Dear

My name is Daniel Gagne and I am currently a nurse and a student in the Master of Nursing programme at the University of Manitoba. I am writing to inform you of a research project that I am commencing to complete the Master of Nursing programme. The study is supervised by Dr. Roberta Woodgate from the University of Manitoba, Faculty of Nursing. The research study is entitled: *The Lived Experience of Patients and Families Transitioning Through 100 Days Post Allogeneic Stem Cell Transplant*. For the purpose of this study, I will be interviewing allogeneic stem cell recipients and their family members.

For the purpose of this research study, I would require you to be the initial contact person with all potential participants by providing them an introductory letter. This would require you to give a letter of introduction to all potential SCT recipients meeting the following inclusion criteria:

- (1) Is able to read, write and speak English,
- (2) Is an individual 18 years of age or older,
- (3) Is an individual between day 0 and 5 years post-allogeneic SCT.

After receiving the introductory letter, would either contact the researcher themselves or provide you with their name and phone number. You would then forward the participant's name and phone number to the researcher by email or phone with the participant's permission by email or telephone.

I would very much like to meet with you, at your earliest convenience, in order to provide you with more information about the research study. Please call _____ or email _____

Sincerely,

Daniel Gagne, RN, BN, BA
Master of Nursing Student

Appendix G: Script for Meeting Between Researcher and BMT Nurse Clinician and Post HSCT Registered Nurses

Hello _____

My name is Daniel Gagne and I am currently a nurse and a student in the Master of Nursing programme at the University of Manitoba. I am commencing a research project to complete the Master of Nursing programme. The study is supervised by Dr. Roberta Woodgate from the University of Manitoba, Faculty of Nursing. The research study is entitled: *The Lived Experience of Patients and Families Transitioning Through 100 Days Post Allogeneic Stem Cell Transplant*.

I am interested in understanding each family member's experience during the first 100 days post myeloablative allogeneic stem cell transplant, but there is very little written about it in nursing and other professional journals. I believe as nurses and other professionals, who care for patients and their families, we need to understand the experience as much as we can. I know it will not be exactly the same for each family or each family member, and this is the reason I have chosen to study each family member for this study.

I will interview each family member twice. Each interview will take one to two hours to complete and will be audio-taped recorded. I will also ask each family member to keep an optional journal about their experience.

For the purpose of this research study, I would require you to be the initial contact person with all potential participants by providing them an introductory letter. (*Give a copy of the Introductory Letter to the BMT Nurse Clinician*). This would require you to give a letter of introduction to all potential SCT recipients meeting the following criteria:

- (1) Is able to read, write and speak English,
- (2) Is an individual 18 years of age or older,
- (3) Is an individual between day 0 and 5 years post-allogeneic SCT.

After potential participants have received the introductory letter, would either contact the researcher themselves or provide you with their name and phone number. You would then forward the participant's name and phone number to the researcher by email or phone with the participant's permission by email or telephone. Are there any questions you would like to ask about the study?

Appendix H: Informed Consent for BMT Nurse Clinician and Post BMT Registered Nurses (page 1 of 3)



Faculty of Nursing

Faculty of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7456
Fax: (204) 474-7682

Research Project Title: The Lived Experience of Family Members Transitioning Through 100 Days Post Allogeneic Stem Cell Transplantation

Study's Researcher: Daniel Gagne **Phone:** XXX-XXXX
Thesis Committee:

Supervisor: Dr. Roberta Woodgate **Phone:** XXX-XXXX
University of Manitoba, Faculty of Nursing

Internal Examiner: Dr. Susan McClement
University of Manitoba, Faculty of Nursing

External Member: Dr. Matthew Seftel
University of Manitoba, Faculty of Medicine

This request form, a copy of which will be left with you for your records and reference, is part of the recruitment process. It should give you the basic idea of what the research is about and the parameters of your participation in the recruitment process. If you would like more detail about something mentioned here, or information not included here, feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, volunteer to participate in the recruitment process in the above study. I understand that the purpose of this study is to better understand each family member's experience during the first 100 days post myeloablative allogeneic stem cell transplant. By learning about this experience, health care providers may be able to help other families. I have been given written information about the study. I have read the information and any questions I had have been answered.

I understand the study is being done by a registered nurse, Daniel Gagne, a student in the Master of Nursing Programme at the University of Manitoba, for his thesis.

Appendix H: Informed Consent for BMT Nurse Clinician and Post BMT Registered Nurses (page 2 of 3)

Dr. Roberta Woodgate, from the University of Manitoba, Faculty of Nursing will supervise the study.

I understand that if I agree to participate in the recruitment process for this study, I will be asked to follow a prepared script when giving the letter of invitation to SCT recipients meeting the following inclusion criteria:

- (1) Is able to read, write and speak English;
- (2) Is an individual 18 years of age or older;
- (3) Is an individual between day 0 and 5 years post-allogeneic SCT.

I understand that my role in the recruitment process for this research is limited to:

- (1) Identifying potential participants meeting the above inclusion criteria;
- (2) Reading the prepared script to potential participants;
- (3) Giving the letter of invitation to potential participants;
- (4) Collecting the name and phone number of the potential participants if they give permission;
- (5) Redirecting potential participants to the researcher if they have any questions;
- (6) Transferring the contact information of potential participants to the researcher by either phone (XXX-XXXX) or by email (XXXXX).

I understand that there are no direct benefits for me to participate in the study. However, I understand that this study will result in knowledge that will help professionals with guidance on how to better support families whose member has undergone an allogeneic stem cell transplant.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, the family's identity would not be discussed or revealed to anyone. Only Daniel will have access to their names. As well, I understand that in all instances, their names and identities would not be discussed or revealed to anyone. I am aware that their names will be replaced with a code number so that no one will be able to identify participants. I understand that only Dr. Woodgate and Daniel will have access to the interviews. I also understand that the other members of the thesis committee, Dr. Susan McClement and Dr. Matthew Seftel will only have access to the summary of the aggregate/collective data. I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). I understand that all data including the audiotapes, interview transcripts, journal notes, field notes, and demographic information will be stored in a locked filing cabinet and computer protected by a password known only to Daniel. I understand that all data will be destroyed following completion of the study.

**Appendix H: Informed Consent for BMT Nurse Clinician and Post BMT
Registered Nurses (page 3 of 3)**

My signature on this form indicates that I have understood to my satisfaction my role and the limitations of my role in the recruitment process in the research project and agree to participate as a recruiter. I understand that I may contact Daniel Gagne (XXX-XXX-XXXX) or Dr. Roberta Woodgate (XXX-XXX-XXXX) if I have concerns, questions or need clarifications or additional information.

I understand that this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and the Health Sciences Centre, Winnipeg, Manitoba. If I have any concerns or complaints about this project, I may contact any of the above named persons or the Human Secretariat (XXX-XXX-XXXX) or email XXXXXX copy of this consent form has been given to me to keep for my records and reference.

Signature of Nurse Recruiter

Date

Signature of Researcher

Date

Appendix I: Script for Meeting between BMT Nurse Clinician or Post BMT Registered Nurses and Potential Participant (when giving Letter of Invitation)

Hello _____

My name is _____. I have been asked by Daniel Gagne, a student in the Master of Nursing programme at the University of Manitoba to provide you with the following letter of invitation. (BMT nurse clinician hands over letter of invitation to SCT recipient)

Daniel is interested in understanding each family member's experience during the first 100 days post myeloablative allogeneic stem cell transplant, but there is very little written about it in nursing and other professional journals. Daniel believes nurses and other professionals, who care for patients and their families, need to understand the experience as much as they can. Daniel knows it will not be exactly the same for each family or each family member, and this is the reason he has chosen to study each family member for this study.

Thank you for your time and for considering this study.

.....

If a SCT recipient is interested to give his name and phone number:

SCT recipient name: _____

SCT recipient phone number: _____

Thank you

Appendix J: Letter of Invitation for Potential Participants**Faculty of Nursing**

Faculty of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7456
Fax: (204) 474-7682

Dear Participant,

My name is Daniel Gagne, and I am a student in the Master of Nursing programme at the University of Manitoba. To complete my nursing programme, I am doing a research project to better understand each family member's experience during the first 100 days post allogeneic stem cell transplant. I believe that a better understanding of this experience can help nurses and other health care professionals who work with patients and their families during this crucial time.

It is my intention to interview a small group of patients and their families who have undergone an allogeneic stem cell transplant. Patients and their family members will be interviewed twice. However, all participants have the option to decline the second interview. Participation in all interviews is voluntary and it will be left to participating patients and their family members to decide how many times they want to be interviewed. Each interview will take approximately one to two hours to complete and will be tape-recorded. The identity of any patients and their family members will be kept confidential. After each interview, I will put the information together and write up the results. You will be provided with a finalized summary of the research study if you would like one.

If you and your family members are interested or have any questions, you can call or email me directly. If you and your family members decide to participate after talking to me, we will set up an interview time convenient for each individual family member. If you and your family members decide not to participate, you can say no without any problem. Participation is voluntary.

Thank you for your time and for considering my study.

Yours sincerely,

Daniel Gagne, RN, BN, BA
Master of Nursing Student
University of Manitoba

Contact: XXX-XXXX or email XXXX

Appendix K: Researcher's Telephone Script (page 1 of 4)

Hello _____

My name is Daniel Gagne, and I am a student in the Master of Nursing programme at the University of Manitoba. You have received some information about a study I am doing and you are willing to hear more about it.

I am interested in understanding each family member's experience during the first 100 days post allogeneic stem cell transplant, but there is very little written about it in nursing and other professional journals. I believe as nurses and other professionals, who care for patients and their families, we need to understand the experience as much as we can. I know it will not be exactly the same for each family or each family member, and this is the reason I have chosen to study each family member for this study. The family members will be determined by you and need to be able to read and write English, must be 18 years of age or older and agree to participate in two interviews.

I will interview each family member twice and each interview will take one to two hours to complete and will be audio-taped recorded.

I will type the interviews, and then I will read them and look for common issues and concerns. The supervisor of my work, Dr. Roberta Woodgate, may also read the interviews. The other members of my thesis committee Dr. Susan McClement from the University of Manitoba and Dr. Mathew Seftel from CancerCare Manitoba will only have access the summary of the aggregate/collective data (i.e., summary of the analyzed data). I will be the only person who knows the identity of each family member. All names will be replaced with a code. Considerable precautions will be taken to safeguard your identity during data collection and presentations. This may include using fictitious names, not sharing detailed information about you such as occupation and diagnosis, information may be slightly distorted or fairly general information may be provided. The tapes and transcripts will be securely stored and destroyed when the study is completed.

The information I get from the interviews will be written up for my thesis. It is also my intention to publish the study in a professional journal and present it at a professional meeting. In all instances, your family's identity would not be discussed or revealed to anyone. You and each family member will be given the opportunity to receive a summary of the study.

If you and your family members agree to participate, he/she can drop out of the study at anytime, ask to stop the interview at any point, or refuse to answer any question.

Participating in this study is entirely voluntary and if you decide not take part in this study, it will not affect your health care. Even if you decide to take part in this study, you may withdraw at any time and/or refrain from answering any questions without prejudice

Appendix K: Researcher's Telephone Script (page 2 of 4)

or consequence. Are there any questions you would like to ask about the study? Do you think you and your family members would like to participate in this study?

(If “no”) Thank you very much for your time. I appreciate having the opportunity of speaking with you.

(If “I would like to think about it”) I would certainly appreciate you doing that. When should I call you back to get your decision?

(If “yes”) Thank you for your interest. To which family member may I describe the study? _____ May I describe the study to _____ now?

(If “no, not available”) When should I get back to _____ about the study?

When we meet, I will ask you to sign a consent saying you will participate based on the information you have been given, and I will ask you to fill out a short form for background information on you and your family. For the interview, it may be helpful to think about your feelings about this experience and any events or decisions that stick out in your mind. I am interested in your thoughts, ideas and views on what it is like for the first 100 days after a family member has received a stem cell transplant. This may include things that have helped, have got in the way or been more difficult.

Thank you for your time. I look forward to meeting you on _____ at _____ at _____.

Family Member

(If “yes”) Hello _____

My name is Daniel Gagne, and I am a student in the Master of Nursing programme at the University of Manitoba. I have been told by (patient) that you have received some information about a study I am doing and you are willing to hear more about it.

I am interested in understanding each family member's experience during the first 100 days post allogeneic stem cell transplant, but there is very little written about it in nursing and other professional journals. I believe as nurses and other professionals, who care for patients and their families, we need to understand the experience as much as we can. I know it will not be exactly the same for each family or each family member, and this is the reason I have chosen to study each family member for this study. The family members need to be able to read and write English, must be 18 years of age or older and agree to participate in two interviews.

Appendix K: Researcher's Telephone Script (page 3 of 4)

I will interview each family member twice and each interview will take one to two hours to complete and will be audio-taped recorded.

I will type the interviews, and then I will read them and look for common issues and concerns. The supervisor of my work, Dr. Roberta Woodgate, may also read the interviews. The other members of my thesis committee Dr. Susan McClement from the University of Manitoba and Dr. Mathew Seftel from CancerCare Manitoba will only have access the summary of the aggregate/collective data (i.e., summary of the analyzed data). I will be the only person who knows the identity of each family member. All names will be replaced with a code. Considerable precautions will be taken to safeguard your identity during data collection and presentations. This may include using fictitious names, not sharing detailed information about you such as occupation and diagnosis, information may be slightly distorted or fairly general information may be provided. The tapes and transcripts will be securely stored and destroyed when the study is completed.

The information I get from the interviews will be written up for my thesis. It is also my intention to publish the study in a professional journal and present it at a professional meeting. In all instances, your family's identity would not be discussed or revealed to anyone. You and each family member will be given the opportunity to receive a summary of the study.

Participating in this study is entirely voluntary and if you decide not take part in this study, it will not affect the health care of (patient). Even if you decide to take part in this study, you may withdraw at any time and/or refrain from answering any questions without prejudice or consequence. If you agree to participate, you can drop out of the study at anytime, ask to stop the interview at any point, or refuse to answer any question. Are there any questions you would like to ask about the study? Do you think you would like to participate in this study?

(If "no") Thank you very much for your time. I appreciate having the opportunity of speaking with you.

(If "I would like to think about it") I would certainly appreciate you doing that. When should I call you back to get your decision?

(If "yes") Thank you for your interest. When would be a good time to do the first interview? Would you like to do it at your home? (If "no") where would you like to do it?

When we meet, I will ask you to sign a consent saying you will participate based on the information you have been given, and I will ask you to fill out a short form for background information on you and your family. For the interview, it may be helpful to think about your feelings about this experience and any events or decisions that stick out

Appendix K: Researcher's Telephone Script (page 4 of 4)

in your mind. I am interested in your thoughts, ideas and views on what it is like for the first 100 days after a family member has received a stem cell transplant. This may include things that have helped, have got in the way or been more difficult.

Thank you for your time. I look forward to meeting you on _____ at _____
_____ at _____.

(Any questions that arise out of this conversation will be answered and noted on this sheet)

Appendix L: Informed Consent for Stem Cell Recipient (page 1 of 3)**Faculty of Nursing**

Faculty of Nursing
 Helen Glass Centre for Nursing
 Winnipeg, Manitoba
 Canada R3T 2N2
 Telephone: (204) 474-7456
 Fax: (204) 474-7682

Research Project Title: The Lived Experience of Family Members Transitioning Through 100 Days Post Allogeneic Stem Cell Transplantation

Study's Researcher: Daniel Gagne **Phone:** XXX-XXXX
Thesis Committee:

Supervisor: Dr. Roberta Woodgate **Phone:** XXX-XXXX
 University of Manitoba, Faculty of Nursing

Internal Examiner: Dr. Susan McClement
 University of Manitoba, Faculty of Nursing

External Member: Dr. Matthew Seftel
 University of Manitoba, Faculty of Medicine

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, volunteer to participate in the above study. I understand that the purpose of this study is to better understand each family member's experience during the first 100 days post allogeneic stem cell transplant. By learning about this experience, health care providers may be able to help other families. I have been given written information about the study. I have read the information and any questions I had have been answered.

I understand the study is being done by a registered nurse, Daniel Gagne, a student in the Master of Nursing Programme at the University of Manitoba, for his thesis. Dr. Roberta Woodgate, from the University of Manitoba, Faculty of Nursing will supervise the study.

Appendix L: Informed Consent for Stem Cell Recipient (page 2 of 3)

I understand that if I agree to participate in the study, I will be asked to participate in two interviews carried out by Daniel. The interviews will be audiotape-recorded and each will take about 1 to 2 hours. During the interview, I will be asked about my experiences as a stem cell recipient. I understand that although two interviews are planned, if additional interviews are needed, it will be up to me how many interviews that I want to take part in. I understand that Daniel will need to get my permission to participate in the second interview, just like the first interview. I understand that all interviews will be audiotape-recorded. The interviews will take place at a time and place convenient to me. I also understand that after each interview, Daniel will record field notes that describe his observations, reflections and potential arising themes. These notes will be kept confidential except to be shared with his supervisor to aid in analysis of the data. I will also be asked to complete a Demographic Form for background information about my family and myself, which will take about 5 to 10 minutes to complete.

I understand that my participation in this study is entirely voluntary and that if I decide to not take part in the study, this will not affect my health care. I understand that even if I decide to take part, I can withdraw at any time and/or refrain from answering any questions I prefer to omit, without prejudice or consequence.

I understand that there are no direct benefits for me to participate in the study. However, I understand that this study will result in knowledge that will help professionals with guidance on how to better support families whose member has undergone an allogeneic stem cell transplant. I understand that there are no undue risks to me in the study. However, I am aware that having the opportunity to talk about my experiences with allogeneic stem cell transplants may make me more aware of some of my feelings. If I become upset or if I need to talk to someone about my feelings, I understand that counselling services will be offered by CancerCare Manitoba.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, my or my family's identity would not be discussed or revealed to anyone. Only Daniel will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that my name will be replaced with a code number so that no one will be able to identify me. I understand that only Dr. Woodgate and Daniel will have access to the interviews. I also understand that the other members of the thesis committee, Dr. Susan McClement and Dr. Matthew Seftel will only have access to the summary of the aggregate/collective data (i.e., summary of the analyzed data). I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). I understand that all data including the audiotapes, interview transcripts, field notes, and demographic information will be stored in a locked filing cabinet and computer protected by a password known only to Daniel. I understand that all data will be destroyed following completion of the study.

Appendix L: Informed Consent for Stem Cell Recipient (page 3 of 3)

I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate as a subject. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand that I may contact Daniel Gagne (XXX-XXX-XXXX) or Dr. Roberta Woodgate (XXX-XXX-XXXX) if I have concerns, questions or need additional information.

I understand that this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba, CancerCare Manitoba and the Health Sciences Centre, Winnipeg, Manitoba. If I have any concerns or complaints about this project, I may contact any of the above named persons or the Human Secretariat (XXX-XXX-XXXX) or email [XXXXXXXXXX](#). A copy of this consent form has been given to me to keep for my records and reference.

Signature of Participant

Date

Signature of Researcher

Date

.....

I would like a summary report of the findings

☐ Yes

☐ No

Please mail a summary of the report of the findings to:

Name

Address

Postal Code

Appendix M: Informed Consent for Family Member (page 1 of 3)**Faculty of Nursing**

Faculty of Nursing
 Helen Glass Centre for Nursing
 Winnipeg, Manitoba
 Canada R3T 2N2
 Telephone: (204) 474-7456
 Fax: (204) 474-7682

Research Project Title: The Lived Experience of Family Members Transitioning Through 100 Days Post Allogeneic Stem Cell Transplantation

Study's Researcher: Daniel Gagne **Phone:** XXX-XXXX
Thesis Committee:

Supervisor: Dr. Roberta Woodgate **Phone:** XXX-XXXX
 University of Manitoba, Faculty of Nursing

Internal Examiner: Dr. Susan McClement
 University of Manitoba, Faculty of Nursing

External Member: Dr. Matthew Seftel
 University of Manitoba, Faculty of Medicine

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

I, _____, volunteer to participate in the above study. I understand that the purpose of this study is to better understand each family member's experience during the first 100 days post allogeneic stem cell transplant. By learning about this experience, health care providers may be able to help other families. I have been given written information about the study. I have read the information and any questions I had have been answered.

I understand the study is being done by a registered nurse, Daniel Gagne, a student in the Master of Nursing Programme at the University of Manitoba, for his thesis. Dr. Roberta Woodgate, from the University of Manitoba, Faculty of Nursing will supervise the study.

I understand that if I agree to participate in the study, I will be asked to participate in two interviews carried out by Daniel. The interviews will be audiotape-recorded and

Appendix M: Informed Consent for Family Member (page 2 of 3)

each will take about 1 to 2 hours. During the interview, I will be asked about my experiences as a family member of a patient who received an allogeneic stem cell transplant. I understand that although two interviews are planned, if additional interviews are needed, it will be up to me how many interviews that I want to take part in. I understand that Daniel will need to get my permission to participate in the second interview, just like the first interview. I understand that all interviews will be audiotape-recorded. The interviews will take place at a time and place convenient to me. I also understand that after each interview, Daniel will record field notes that describe his observations, reflections and potential arising themes. These notes will be kept confidential except to be shared with his supervisor to aid in analysis of the data. I will also be asked to complete a Demographic Form for background information about my family and myself, which will take about 5 to 10 minutes to complete.

I understand that my participation in this study is entirely voluntary and that if I decide to not take part in the study, this will not affect the health care of my family member who has undergone an allogeneic stem cell transplant. I understand that even if I decide to take part, I can withdraw at any time and/or refrain from answering any questions I prefer to omit, without prejudice or consequence.

I understand that there are no direct benefits for me to participate in the study. However, I understand that this study will result in knowledge that will help professionals with guidance on how to better support families whose member has undergone an allogeneic stem cell transplant. I understand that there are no undue risks to me in the study. However, I am aware that having the opportunity to talk about my experiences with stem cell transplants may make me more aware of some of my feelings. If I become upset or if I need to talk to someone about my feelings, I understand that counselling services will be offered by CancerCare Manitoba.

I understand that findings from this study may be presented at a health or educational conference or published in a professional journal. In all instances, my or my family's identity would not be discussed or revealed to anyone. Only Daniel will have access to our names. As well, I understand that in all instances, our names and identities would not be discussed or revealed to anyone. I am aware that my name will be replaced with a code number so that no one will be able to identify me. I understand that only Dr. Woodgate and Daniel will have access to the interviews. I also understand that the other members of the thesis committee, Dr. Susan McClement and Dr. Matthew Seftel will only have access to the summary of the aggregate/collective data (i.e., summary of the analyzed data). I understand that confidentiality will be maintained except in situations in which there is a legal requirement to disclose identity (i.e., abuse situations). I understand that all data including the audiotapes, interview transcripts, journal notes, field notes, and demographic information will be stored in a locked filing cabinet and computer protected by a password known only to Daniel. I understand that all data will be destroyed following completion of the study.

Appendix M: Informed Consent for Family Member (page 3 of 3)

I understand that if I decide to participate in the study, a summary of the study will be provided to me if requested.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate as a subject. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand that I may contact Daniel Gagne (XXX-XXXX) or Dr. Roberta Woodgate (XXX-XXXX) if I have concerns, questions or need additional information.

I understand that this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba CancerCare Manitoba and the Health Sciences Centre, Winnipeg, Manitoba. If I have any concerns or complaints about this project, I may contact any of the above named persons or the Human Secretariat (XXX-XXXX) or email XXXXXXXXXXXX A copy of this consent form has been given to me to keep for my records and reference.

Signature of Participant

Date

Signature of Researcher

Date

.....

I would like a summary report of the findings

☐ Yes

☐ No

Please mail a summary of the report of the findings to:

Name

Address

Postal Code

Appendix N: Demographic Data Form for Stem Cell Recipient**ID # :** _____**Date:** _____

Information gathered in this form will help us get to know you and your family better.
All information will be kept confidential.

1. How old are you? _____ (years)
2. Gender: ☐ Female ☐ Male
3. Are you: ☐ Married ☐ Single ☐ Divorced
 ☐ Separated ☐ Widowed
4. Do you have children? ☐ Yes ☐ No

If so, how many children do you have in your family? _____

How old are they, what grades are they currently enrolled in, and are they boys or girls?

Age	Sex	Grade level/Daycare
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

5. Do you live in the city or outside the city?
☐ In the city
☐ Outside the city Where: _____
6. What type of employment did you have prior to the stem cell transplant?

When was the last time you worked?

Thank you for helping us learn more about the needs and support experiences of families with a member undergoing a stem cell transplant.

Appendix O: Demographic Data Form for Family Members**ID # :** _____**Date:** _____

Information gathered in this form will help us get to know you and your family better.
All information will be kept confidential.

1. What is your relationship to _____ ?

2. How old are you? _____ (years)

3. Gender: ☐ Female ☐ Male

4. Are you: ☐ Married ☐ Single ☐ Divorced
☐ Separated ☐ Widowed

5. Do you have children? ☐ Yes ☐ No

If so, how many children do you have in your family? _____

How old are they, what grades are they currently enrolled in, and are they boys or girls?

Age	Sex	Grade level/Daycare
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

6. Do you live in the city or outside the city?
☐ In the city
☐ Outside the city Where: _____

8. Are you currently working full-time or part-time?
☐ Not working
☐ Full-time
☐ Part-time, please indicate the number of hours per week. _____
☐ Other (please specify): _____

Thank you for helping us learn more about the needs and support experiences of families
with a member undergoing a stem cell transplant.

Appendix P: Interview Guide for Stem Cell Recipient (page 1 of 3)

Introduction to the interview: I would like to learn more about what it is like to go through an allogeneic stem cell transplant. I would like you to share your experiences from the time prior to your diagnosis to 100 days post stem cell transplant. To help tell your story, I will be asking you a series of questions. I would like you to talk about the changes that occurred in your life, the type of needs that you had, the type of support and help you received, the ways that you coped, and anything else or thoughts or feelings that come to mind.

NOTE: (PROBES WILL ONLY BE ASKED AS NECESSARY. THEY ARE MEANT TO STIMULATE DISCUSSION.)

1. Can you please tell me a little more about your family and life before you became ill and decided to have a stem cell transplant?

Probes:

- What was day-to-day life for you and your family?
- Can you give me some examples?
- What things or events stuck out in your mind during this period?
- Tell me about some good times or experiences that you and your family had during this period?
- Tell me about any really bad\difficult times or experiences that you and your family had during this period?
- How did you feel during this period?
- What type of things did you do to cope when having problems?
- Who did you go to when you wanted help?
- What kind of things did you need help with?

2. Can you please tell me what it was like when you became ill and its impact on your life?

Probes:

- What was day-to-day life for you and your family?
- Can you give me some examples?
- What things or events stuck out in your mind during this period?
- Tell me about some good times or experiences that you and your family had during this period?
- Tell me about any really bad\difficult times or experiences that you and your family had during this period?
- How did you feel during this period?
- What type of things did you do to cope when having problems?
- Who did you go to when you wanted help?
- What kind of things did you need help with?

Appendix P: Interview Guide for Stem Cell Recipient (page 2 of 3)

3. Can you please tell me about when you decided to undergo a stem cell transplant?

- Probes:**
- What was day-to-day life for you and your family?
 - Can you give me some examples?
 - What do you remember most about that time?
 - What things or events stuck out in your mind during this period?
 - What did you feel like?
 - What initial impact did it have on your life?
 - What helped (or did not help) you during this period?
 - When you were first introduced to stem cell transplantation, what thoughts were going through your head?

4. Tell me about some good times or experiences that you and your family had during the 100 days after your stem cell transplant?

- Probes:**
- Can you give me some examples?
 - What things or events stick out in your mind during this period?
 - How did you feel during this period?

5. Tell me about any really bad/difficult times or experiences that you and your family had during the 100 days after your stem cell transplant?

- Probes:**
- Can you give me some examples?
 - What things or events stick out in your mind during this period?
 - How did you feel during this period?

6. What type of things did you do to cope when having problems?

- Probes:**
- Can you give me some examples?
 - What things or events stick out in your mind during this period?
 - How did you feel during this period?
 - Who did you go to when you wanted help?
 - What kind of things did you need help with?
 - Was there anything that you feel would have helped you?
 - Who else (e.g. friends) or what else (e.g. religious support) besides your family was a part of your life during this period?

7. What advice would you offer to other stem cell recipients and their families?

- Probes:**
- What advice would you give to them that would help to get them through it?
 - What suggestions would you have for others going through a similar situation?

Appendix P: Interview Guide for Stem Cell Recipient (page 3 of 3)

8. Some people would consider a stem cell transplant as a major transition or life event. Do you see a stem cell transplant as a major transition or life event? Please explain.
- Probes:**
- How different is it to other transitions that you have experienced?
 - Please explain?
9. What advice would you offer health care professionals that would help them to better care for stem cell recipients and their families?
- Probes:**
- What helped you?
 - Was there anything health care providers said or did that made the time more difficult?
 - What was the most difficult part of the experience?
 - What do you think contributed to your adjustment?
10. Is there anything else you would like to talk about that you feel is important for me to know?

Appendix Q: Interview Guide for Family Member (page 1 of 3)

Introduction to the interview: I would like to learn more about what it is like to go through an allogeneic stem cell transplant. I would like you to share your experiences from the time prior to your diagnosis to 100 days after the transplant. To help tell your story, I will be asking you a series of questions. I would like you to talk about the changes that occurred in your life, the type of needs that you had, the type of support and help you received, the ways that you coped, and anything else or thoughts or feelings that come to mind.

NOTE: (PROBES WILL ONLY BE ASKED AS NECESSARY. THEY ARE MEANT TO STIMULATE DISCUSSION.)

1. Can you please tell me a little more about your family, life, and your relationship to (SCR) before they became ill and decided to have a stem cell transplant?

Probes:

- What was day-to-day life for you and your family?
- Can you give me some examples?
- What things or events stuck out in your mind during this period?
- Tell me about some good times or experiences that you and your family had during this period?
- Tell me about any really bad\difficult times or experiences that you and your family had during this period?
- How did you feel during this period?
- What type of things did you do to cope when having problems?
- Who did you go to when you wanted help?
- What kind of things did you need help with?

2. Can you please tell me what it was like when (SCR) became ill and its impact on your life and family?

Probes:

- What was day-to-day life for you and your family?
- Can you give me some examples?
- What things or events stuck out in your mind during this period?
- Tell me about some good times or experiences that you and your family had during this period?
- Tell me about any really bad\difficult times or experiences that you and your family had during this period?
- How did you feel during this period?
- What type of things did you do to cope when having problems?
- Who did you go to when you wanted help?
- What kind of things did you need help with?

Appendix Q: Interview Guide for Family Member (page 2 of 3)

3. Can you please tell me about when (SCR) decided to undergo a stem cell transplant?

Probes:

- What was day-to-day life for you and your family?
- Can you give me some examples?
- What do you remember most about that time?
- What things or events stuck out in your mind during this period?
- What did you feel like?
- What initial impact did it have on your life?
- What helped (or did not help) you during this period?
- When you were first introduced to stem cell transplantation, what thoughts were going through your head?

4. Tell me about some good times or experiences that you and your family had during the first 100 days after the stem cell transplant?

Probes:

- Can you give me some examples?
- What things or events stick out in your mind during this period?
- How did you feel during this period?

5. Tell me about any really bad\difficult times or experiences that you and your family had during the first 100 days after the stem cell transplant?

Probes:

- Can you give me some examples?
- What things or events stick out in your mind during this period?
- How did you feel during this period?

6. What type of things did you do to cope when having problems?

Probes:

- Can you give me some examples?
- What things or events stick out in your mind during this period?
- How did you feel during this period?
- Who did you go to when you wanted help?
- What kind of things did you need help with?
- Was there anything that you feel would have helped you?
- Who else (e.g. friends) or what else (e.g. religious support) besides your family was a part of your life during this period?

7. What advice would you offer to other families of stem cell recipients?

Probes:

- What advice would you give to them that would help to get them through it?
- What suggestions would you have for others going through a similar situation?

Appendix Q: Interview Guide for Family Member (page 3 of 3)

8. Some people would consider a stem cell transplant as a major transition or life event. Do you see a stem cell transplant as a major transition or life event? Please explain.

Probes:

- How different is it to other transitions that you have experienced?
- Please explain?

9. What advice would you offer health care professionals that would help them to better care for stem cell recipients and their families?

Probes:

- What helped you?
- Was there anything health care providers said or did that made the time more difficult?
- What was the most difficult part of the experience?
- What do you think contributed to your adjustment?

10. Is there anything else you would like to talk about that you feel is important for me to know?